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PREFACE

This Comparative Framework is one of the main products of the European Project 'STEPS – Structures towards emancipation, participation and solidarity'. STEPS was funded from October 2001 to August 2004 through the Community Action Programme to combat Discrimination by the European Commission, DG Employment and Social Affairs. In the STEPS project 18 universities, service providing organisations and administrations worked in collaboration locally, nationally and cross-nationally. It was coordinated by Anne Ernst and Prof. Dr. Michael Langhanky from the Protestant University of Applied Sciences for Social Work, Hamburg, and Dr. Dorothee Bittscheidt from the HWP – Hamburg University for Economics and Politics.

We would like to thank the colleagues, who contributed to the Comparative Framework: Hector MEDORA, Social Service Department of the Royal Borough of Kensington & Chelsea, Zenobia NADIRSHAW, Kensington & Chelsea Primary Care Trust, Bart BRANDERHORST and Els VAN KOOTEN, Stichting PameijerKeerkring Rotterdam, Isabel PAULA, Universitat de Barcelona, and Kent ERICSSON, Uppsala Universitet.

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SECTION 1. OVERVIEW

Paul Cambridge and Anne Ernst

1.1.   INTRODUCTION AND BACKGROUND

Cross-national studies in social care have received increasing funding within the European context, including projects in learning disability (Ernst, 2002; Weinbach, 2004). The main challenges for such research and development studies are the contrasting local and national characteristics of services themselves, but also the different policy backcloths and welfare traditions against which local service characteristics are placed. Although comparative welfare state research (e.g. Esping-Andersen, 1990; Alber, 1995; Committee on the Rehabilitation and Integration of People with Disabilities, 2002; European Commission, 2003; Aselmeier and Weinbach, 2003) provides generic conceptual frameworks for understanding and comparing different systems and traditions, gaps on the details of service organisation and process remain starkly evident. These are found within and between the main adult client groups of social care as well as between policy and practice. STEPS provided an opportunity to identify and examine such gaps by analysing difference and diversity as well as similarities and convergence at local and national levels and through broader cross-national comparison.

The STEPS anti-discrimination and learning disability agenda (Ernst, 2002) immediately raised compounding issues of contrast and diversity relating to gender, race, ethnicity, culture, age and sexuality, as well as disability per se. Such diversity is however characteristic of post-modern analysis, within the competing trends of globalisation, supra-nationalism and Europeanisation on the one hand and the emerging realisation and acceptance of the importance of national and local difference on the other. Such cross-national comparisons therefore present a particular challenge for research in social policy (Kennett, 2001).

The link between policy implementation and practice is an important social policy theme in de-institutionalisation and learning disability (Mansell and Ericsson, 1996) and is likely to become similarly important in anti-discrimination and learning disability. Policy initiatives tied to evaluation and demonstration have aimed to establish such connections (Knapp et al, 1992; Cambridge et al, 1994), but within national confines. Cross-national comparison has consequently tended to be post-hoc, comprising descriptive national accounts, accompanied by attempts to standardise statistics, for example:

> *'These data are drawn from different sources and there are some minor inconsistencies between and discontinuities within, the national series, but the overall trends and levels illustrate the nature of the changes which have taken place.'* (Mansell and Ericsson, 1996, p. 3)

Robust comparative studies in social care are required which examine differences in practice and implementation as well as differences at the general policy level. There is consequently a need to refine and develop comparative methodologies, underlined by the increased level of funding for such projects from the European Union and the development of European level funding and intervention in social care.

Carnaby (1997), drawing on Jones (1985) summarised three main advantages to cross-national research:

- a capacity to promote a clearer understanding of the home environment by providing a reference point outside the cultural frame

- taking lessons from abroad has the potential to broaden ideas and perceptions

- studies which strive to understand the different values underpinning services can help develop the knowledge base

Such studies also provide the potential to better understand how different national systems are organised and work. Reference points outside the cultural frame help with reappraising and examining specific practices and values within a national or local context. Cambridge (1999a) underlined the importance of considering terminology and definitions when making cross-national comparisons and when identifying transferable lessons, referencing different philosophies, employment models, forms of service organisation and economic and political differences. For example the different emphasis national policy and practice places on normalisation, de-institutionalisation and the social care market across Europe. Such variability, it is argued, requires a shared language and

'... the capacity to record and map similarities and differences between services and a broad conceptual framework for informing analysis and interpretation'. (Cambridge, 1999a, p. 4)

The European Intellectual Disability Research Network (IDRESNET) project (Beadle-Brown et al, 2003) supported the value of such comparisons for three key reasons:

- they have the potential to lead to harmonisation of practice and thereby to improvement in the quality of life of people with learning disabilities and to greater social cohesion in the European Union

- improvement in services, as a broad range of possibilities are considered by member states due to dissemination of good practice, increasing the range of possible innovations in service organisation, design and delivery

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

Harmonisation as an aim in itself is of limited value as it will not necessarily lead to improvements in the overall quality of learning disability services or the quality of life of people with learning disabilities. Indeed, it could be argued that by respecting the diversity of local services and appropriate differences between national service and policy systems, quality can be scrutinised and improved in culturally appropriate ways, with transferable lessons identified on the basis of exchange and synergies in practice. Permeability, as a way to improve co-operation and the mobility of good practice is also consequently a potentially important objective.

In relation to human rights and connected principles there are increasing similarities in recognition and definitions across the European countries. Conversely, there remain major differences in respective national legal frameworks, criminal justice systems and access to benefits and services for people with disabilities. These structural differences and supra-national similarities also need to be acknowledged and articulated in any cross-national comparison or analysis.

The working papers of IDRESNET (Beadle-Brown et al, 2003) included comparative accounts from the seven partners (Germany, Spain, Sweden, Greece, Belgium, the Netherlands and England) structured according to five primary dimensions. These were utilised for a comparison of the structure, design and organisation of support for people with learning disabilities (Weinbach, 2004). They covered (1) definitions, legal status and eligibility, (2) policy framework, (3) funding of services and the role of public and private sectors, (4) emerging service structures and models, and (5) experience of people with learning disabilities and their families. In referencing important concepts and principles for learning disability services such as self-determination, normalisation, needs orientation, inclusion and anti-discrimination, Weinbach (2004) observes:

'... applying such principles invariably meets with obstacles, the practical realisation of these concepts varying from country to country. Comparative research offers the chance to design

strategies for development of support systems that effectively improve the quality of life of people with learning disabilities by sharing lessons from other countries.' (Weinbach, 2004, p. 3).

Referencing Anttonen and Sipila (1996), Weinbach also identified three problems relating to cross-national research:

- services come under different fields of administration in different countries

- the dividing line between voluntary and non-voluntary services is ambiguous, and

- comparative social care statistics are limited in the absence of standardisation

The tension between generalisation at the national level and the articulation of local evidence and experience remains a major challenge for cross-national studies in social care. Local service arrangements often form a component of cross-national projects as researchers tend to utilise established links with services in their localities. Recognising the risk of bias, Cambridge (1999a) references the importance of sampling frames for comparative client based studies, noting that broad national or local samples are difficult to construct and variation in factors such as group or service characteristics difficult to control. Similar problems are evident when comparing services between countries, with various levels of devolution, different policy and legal frameworks, and contrasting organisational and administrative structures and systems. The representative-ness for study site services is consequently a critical factor when generalising at national levels or undertaking cross-national comparisons.

The IDRESNET project addressed this issue with researchers based in their respective national localities and service systems (Siegen in Germany, Barcelona in Spain, Uppsala in Sweden, Thessaloniki in Greece, Ghent in Belgium, Groningen the Netherlands and Canterbury in England) making broad national comparisons across the five primary dimensions outlined above. However, this risks over generalisation at national levels and the loss of insight which local or intra-national comparisons or similarities or differences potentially provide.

Ways of minimising potential differences between study sites have been suggested (Cambridge, 1999a), including restricting comparisons of services or service systems to representative types, such as urban or rural authorities or through the use of descriptive case studies. For example, case studies were utilised by STEPS for identifying and mapping equal opportunities and empowerment issues in learning disability (Cambridge, 2002). Other comparative projects (Schädler and Aselmeier et al, 2004) developed methodologies which attempted to address difficulties of comparison by the use of a wider systems approach within authority or regional level case studies.

In most comparative analyses, descriptions of different national arrangements are generally reported separately. Whilst this provides useful national profiles, overall comparative analysis is consequently sparse or supplementary. The challenge for cross-national research is also therefore to develop conclusions concerning the similarities and differences between national systems, informed by local example and including an explanation of historical, cultural and structural differences.

1.2.   THE STEPS COMPARATIVE FRAMEWORK

It was against this backcloth and challenge that the STEPS (Structures Towards Emancipation, Participation and Solidarity) European learning disability project (Ernst, 2002) developed an explicit comparative framework. This was required in order to develop both general and transferable lessons between the member countries.

The European Action Research Project focused on structures, instruments and methods to combat discrimination against people with learning disabilities and to develop mainstream and community-based services. It is collecting European experiences and examples of good practice with the aim of encouraging full participation and free access to materials and cultural and social resources, such as housing, leisure and work. STEPS was developed within this construct, and one of the defining characteristics of the project – in addition to the overall focus on anti-discrimination and learning disability – was the development of local partnerships in each of the five participating countries (England, Spain, Sweden, the Netherlands and Germany). These partnerships were developed between researchers, local administrations and local services.

However, the construction and form of each local partnership inevitably varied according to the structures, organisations and processes operating in their respective national and local contexts, the particular challenges facing learning disability services nationally and locally and the characteristics of the research relationships themselves. This also raised major challenges for comparison, with comparative analysis further compounded by the fact that as a development and dissemination project, each local partnership focused on a particular theme or innovation relevant to combating the discrimination and exclusion of people with learning disabilities within its local and national system. There were consequently no common development goals at the micro or local level. For example, the English partnership was defined by collaboration between the Tizard Centre at the University of Kent, the Royal Borough of Kensington and Chelsea Social Services Department and Kensington and Chelsea Primary Care NHS Trust, with a development focus on person-centred planning for people with learning disabilities. Other themes included civil rights (Barcelona), seasonal meetings and involving people with learning disabilities (Lidingö/Uppsala), access to work (Rotterdam) and service restructuring and advocacy (Hamburg).

Such variability raised a major challenge for comparison up and above those challenges identified earlier, particularly in relation to the potential transferability of lessons between national and local systems. However, it was also recognised that the exchange of information in its own right generated positive gains and facilitated reflection on specific national and local practices and experience. Hector Medora (Head of Disability and HIV Services, Social Service Department, Royal Borough of Kensington & Chelsea) confirmed:

> *'… it was very helpful in making me clearer about what we needed to say about some things. And I also found that in discussions in our partnership we had sometimes different understandings and opinions about things. So it was a very good process. It does take time and energy, but you come out with mutual understanding of what the problems are.' (*Documentation III. International STEPS-Conference, 2003)

To help with this process, a series of guiding principles were agreed for the development of the comparative framework. The main aims were to reduce technical ambiguities but also to facilitate the exchange of baseline descriptive information on each local and national picture. Following consultation it was agreed that the primary product would be in English, with rules for translation specified. Templates were provided to each partnership to complete, along with examples of completed national frameworks from the English and German partners. The academic members of each of the partnerships and in Rotterdam the representatives of the service providing organisation were responsible for leading this work (see Appendix 1).

Following the completion of the national templates a consultation process followed in which the lead person involved in each of the partnerships was able to reflect on the comparative findings, developed by Paul Cambridge and Anne Ernst on the basis of the STEPS-objectives and values (section 2 of this paper).

The comparative framework was developed between March 2003 and May 2004 and comprised three key components:

1. standard local project/partnership profiles, including summary descriptions and basic data
2. a set of comparative questions and descriptive answers, covering national and local policy and practice themes
3. a glossary of key terms, again organised into themes

1.3. THE FRAMEWORK ELEMENTS

1.3.1. Product 1 – Local partnership profiles

This component of the comparative framework was designed to provide a descriptive profile of the local partnership and its key organisational and operational characteristics. The aim was to enable a clear understanding of respective arrangements and relationships characterising each local partnership (Appendix 2). The impact of the factors covered in product 1 on each partnership could also be articulated. Much of the early discussion within the STEPS project had directly and indirectly focused on explaining such factors in each national and local context and the meanings of the different descriptive terms used. It was anticipated that the development of such baseline accounts, along with their later development through discussion, would help reduce ambiguity and aid mutual understanding and information exchange.

1.3.2. Product 2 – Descriptive questions covering local arrangements within the national context

This component of the comparative framework was conceived as a device to provide a descriptive focus on a series of key organisational, policy and legal dimensions. These were important for aiding an understanding of local working relationships and organisational configurations in services for people with learning disabilities in each of the national partnerships, but also within their respective national policy and welfare contexts. For example, the status and function of local government in England or the system of administration in the autonomous region of Catalonia in Spain. Also included were factors relevant to understanding the various demands experienced and responses developed by the respective local organisational systems stemming from both national and local influences such as policies, resource availability and practice and management imperatives.

Within this overall context, a priority was given to identifying and making visible issues concerning user centred services, for example, user involvement, the integration of people with profound and multiple disabilities, challenging behaviour, advocacy arrangements and individual planning or funding arrangements. The resulting descriptions and themes addressed were directly relevant to the STEPS anti-discrimination focus as well as providing an interpretative baseline for comparing arrangements and experiences across the five STEPS partnerships. Appendix 3 lists the information elicited from each of the five partnerships.

1.3.3. Product 3 – Glossary of terms and service typologies

Focused discussion on issues and themes relevant to the STEPS project at the series of project conferences indicated the usage of a wide variety of terms and definitions across the five national and local contexts. Some terms had unique national or local applications (such as primary care trust or partnership board in the English context), while others had some level of shared meaning across the different national contexts (such as community care or individual payments). As such variability had often led to confusion and as some terms were not readily translated or transferable between national contexts, it was deemed necessary to develop a shared vocabulary and language to aid mutual understanding and information exchange. Each partnership developed a working glossary of key terms and their definition or description.

Each of the national entries for the glossary were organised separately but have since been integrated as far as practicable to provide for a coherent a picture as possible. Depending on their particular service system and arrangements, partnerships emphasised different terms and structural elements, mirroring their respective service typologies. The primary function of the exercise was to provide a shared reference point for interpreting the overall comparative framework and other STEPS reports and to reduce ambiguity, although the glossary also has the potential to be further developed and refined at a future time.

SECTION 2. COMPARATIVE FINDINGS

Paul Cambridge and Anne Ernst

2.1.   INTRODUCTION

A discussion of comparative findings is now undertaken in the context of the main three elements of the comparative framework, drawing on the information contained in each of the five respective national frameworks. The comparative analysis and interpretations below aim to provide an overview rather than detail, of respective national and local arrangements. Reference should consequently be made to the five national frameworks for fuller descriptions and details (sections 4 to 8 below).

Figures 1 to 5 in this chapter provide a summary, in diagramatic form, of the respective national and local service systems in learning disability. They should be used in conjunction with the descriptive comparisons provided below and the comparative analyses in section 3 of this report.

2.2.   PRODUCT 1 – LOCAL PARTNERSHIP PROFILES

The original aim of the STEPS project was that each partner or member country should develop a 'trialogue' between the local administration responsible for services for people with learning disabilities, the services or service providers and academics from a research institution or university working with the services or nearby (Ernst, 2002). However, the organisational, developmental and service contexts which helped define each local partnership differed, largely as a result of some of the factors specified above. Many of the characteristics of each of the local STEPS partnerships were also specifically determined by the various national arrangements for learning disability services discussed later in this report. Consequently, this element of the comparative framework was designed to make the components, nature and determining influences of each partnership more explicit.

2.2.1. HAMBURG

In Germany the government imposes service agreements on the voluntary welfare organisations, which, in line with the principle of subsidiarity, determine the provision of services, with the state bearing the relevant costs. As Hamburg is one of the 16 states of the federal republic of Germany (see 2.3.1 and 2.3.7. below), it has relative autonomy within the framework of federal law. One of the partners is the Hamburg Ministry of Social Welfare and the Family, responsible for social welfare, social assistance, social insurance, care of the elderly, young people, the homeless, people with disabilities, accommodation for refugees and supported employment. Participants in STEPS are members of the Hamburg 'Social Welfare and Integration Department'. Other offices and departments provide mainstream services used by people with learning disabilities, and the Senate's Co-ordinator for Equality of People with Learning Disabilities informs and advices people with learning disabilities and their families.

Figure 1

A Draft of the Hamburg Service System

Taxed financed   *Insurance*   *Insurance*

| INTEGRATION ASSISTANCE FOR HOUSING, WORK AND LEISURE | LONG TERM CARE | HEALTH CARE |

Hamburg Ministry for Social Welfare and Family

| residential services (ca. 90 %) | non-residential/ community based services | from July 2004: personal budget |

service providing organisations   *service providing organisations*

The Foundation Das Rauhe Haus runs a range of services, including services for around 300 people with disabilities. The Protestant Foundation Alsterdorf, is the biggest provider in Hamburg, running a range of services for 1,600 people with learning disabilities. Distributed all over Hamburg, both service providing organisations supply housing services (residential and non-residential/community based), personal assistance and work assistance, day services and employment opportunities (see section 4, product 1, question 2).

Other providers, again mainly from the voluntary sector, are prominent as parent and other specialist organisations, and also offer support and information.

The academic links of the partnership are the Hamburg University for Economics and Politics and the University of Applied Sciences.

At present there is no epidemiological data on people with learning disabilities in Hamburg and no individualised data base on services, costs or individual needs.

Service users are involved as consultants, via arrangements in the service providing organisations such as the legally prescribed advisory boards in residential homes and sheltered workshops and through existing advocacy networks such as People First and Strong Angels (support and training organisation).

The evaluation focus in the German partnership is service restructuring to aid the development of community based services, alongside advocacy and person-centred support.

2.2.2. LONDON – CANTERBURY

Figure 2

A Draft of the Kensington & Chelsea Service System

MACRO

MICRO

Needs Assessment

Eligibility for Services

different state allowances and benefits according to individual entitlement

Partly due to the separation of purchasing from providing and the relatively developed market in social care and partly as a consequence of recent measures aimed at resolving the health and social care divide through partnership working and a single management structure for learning disability services in Kensington and Chelsea, there is no pure administration-provider representation.

The Royal Borough of Kensington and Chelsea (social services department) is the local authority represented. Its partner, which also manages specialist learning disability services, is Kensington and Chelsea Primary Care trust, part of the NHS locally. Together through the Learning Disability Partnership Board, services for people with learning disabilities are jointly planned, funded and purchased.

The academic institution represented is the Tizard Centre, which is part of the School of Social Policy, Sociology and Social Research at the University of Kent at Canterbury, one of the few academic departments working in the specialist field of learning disability in England.

A wide range of services and service provider organisations operate locally in Kensington and Chelsea, largely as a result of a mixed economy of provision of the 1980s having developed into a quasi-market in social care following the 1990 community care reforms (Department of Health, 1989 – see section 5, product 1, question 2).

IT systems hold financial and service planning data on service users needs, service receipt and costs. Individual information on a register is also used for long-term planning. The person-centred planning (PCP) pilot project is also aggregating person-centred planning information to help inform strategic planning.

The Learning Disability Partnership Board has service users and parents as representatives, along with service providing organisations. Advocacy and involvement are therefore part of the working machinery locally, although service users also link into the project and to service development (Equal People (Mencap), People First (self-advocates), It's my life group (elected user representatives), Full of Life (parents) and the Quality Network (users and service providers working together to improve quality)). Other representatives include those local agencies such as education housing and employment, involved with supporting people with learning disabilities or helping manage services which include people with learning disabilities (for example adult education and local authority housing).

The evaluation focus in the English partnership is the development of user-centred services, in particular the introduction of PCP within the overall policy framework of Valuing People (Department of Health, 2001), the national learning disability strategy.

2.2.3. ROTTERDAM

Figure 3

A Draft of the Rotterdam Service System

National Insurance

National Level — **AWBZ (Law)**

Regional Level — **Zorgkantoor (Care office)**

Annual targets

+/+

-/-

(Eligibility) RIO – Regional Indication Organ

Z.I.N. (Zorg in natura/ in-kind transfer)

Care providing organisations

„Production based" (number of service users)

Personal plans

production based budget based on contracts

Person centred budget

20 %

(individual payments)

€

External Support

Relationships in the Dutch partnership are primarily determined by the structural characteristics of services in the Netherlands and their local form in Rotterdam (see Section 6). There is consequently no relationship between the administration (the local Care Office as an arms-length public sector organisation) and local government (the local Rotterdam administration).

The service provider in the partnership is Stichting PameijerKeerkring. As such it is one of three organisations forming the Maaskringgroep, offering a wide range of services and support for people with disabilities in all age groups, including residential services, supported living, work and employment services, education and leisure activities.

Maaskringgroep offers treatment, education and support to young people with (mild) learning disabilities and behavioural disorders, linking into the wider environment and through close co-operation with various social partners. Support is needs led, via assessment and individualised planning. Around seven other service providing organisations offer services in Rotterdam for people with disabilities, concentrating on areas of provision such as housing and living arrangements, such as the Pope John XXIII charity and the Protestant Christian Charity Homes. Parents and disabled adults can access services via the local social work organisation (SPD).

Another partner in STEPS is Stichting OMIJ Rijnmond. OMIJ is a social firm offering work places for persons distanced from the labour market. The firm co-operates with PameijerKeerkring in order to offer work placements for people with learning disabilities with the aim of fostering their integration in the workplace.

There are strong links between services, workers and the academic partner INHOLLAND, where the connections between theory and practice are developed and applied to social work. Professional workers also provide input to teaching programmes.

The central Dutch government and national welfare organisations (e.g. NIZW, the National Institute for Care and Welfare) hold information on numbers and costs but this is not localised, although OMIJ Rijnmond and INHOLLAND have an idea of likely demographic developments and changes.

Service users are represented through a range of local and national organisations. Service users groups include Onderling Sterk (for people with learning disabilities) which is supported by R'go (Social Work) and volunteers. Nationally 'Ons Belang' is active, linking with local branches and with a working relationship with the National Parent Federation (nationally and locally). Patient's platforms are organised at the local level but are mainly for physical care (and cure) issues rather than disability. However, every service provider has its own Client Board, which are relatively active and successful, influencing strategic decisions as well as day to day activities. They also have a strong legal basis, whereas interest groups such as Onderling Sterk and Ons Belang lack a statutory footing. There is also a strong bilateral relationship and contact between the ZK and the service provider.

The evaluation focus in the Rotterdam partnership is access to work, including descriptions of experiences in relation to community-based schemes such as a shop and laundry. Training methods are also included.

2.2.4. LIDINGÖ – UPPSALA

The highly individualised, largely decentralised and relatively autonomous nature of learning disability services in Sweden and Lidingö, frames the characteristics of the local partnership and the evaluation focus.

Without providers as such, the political board for disability services of the local municipality (Department for the Elderly and Disabled) organises and runs disability services itself, providing support through housing and daily activities. A private organisation runs housing, with support for three living groups. Full information is available on the people supported by the administration.

The academic partner is the Department of Education at Uppsala University. Two reference groups are attached to the local partnership for the project, one comprising staff and family representatives and one people with disabilities and their representatives.

The evaluation focus in the Lidingö partnership is the testing and implementation of a method of personal futures planning for people with learning disabilities, called seasonal meetings. The intention is to increase the involvement of people with learning disabilities and their representatives.

Figure 4

A Draft of the Lidingö Service System

2.2.5. BARCELONA

The autonomous region of Catalonia is composed of four provinces (Barcelona, Girona, Lleida, and Tarragona) which in total contain 311 municipalities. The regional government of Catalonia is represented in STEPS in partnership with the Social Welfare Department of the Diputatión of Barcelona. The main responsibilities and activities of the Social Welfare Department are to provide financial and technical support, legal assessment, support to staff, support to non-governmental organisations and to disabled people both in hospitals and concerning social integration. The department runs a day care centre, a respite care centre, and a range of residential services. The Deputatión of Barcelona has developed a strictly municipal model, intended to enable it to fully and effectively meet its primary obligation as an intermediate organ of the local administration and to ensure the integrated provision of municipal services in Barcelona.

The City Council of Barcelona started the European 'Cities of Human Rights' project in 1998, so the Office for Non-Discrimination (OND) represents the City of Barcelona in the Project, inaugurated on 15 December 1998 in response to a growing demand for information from citizens. This is the first municipal office of its kind in Europe, and its function is to defend the rights of people and groups in Barcelona who are discriminated against for reasons of gender and sexuality, membership of a cultural group, physical and mental health problems and age. The OND offers information, legal advice, mediation in disputes and work in the fields of identification and prevention of discrimination.

Figure 5

A Draft of the Catalan Service System

The foundation ASPANIAS is the second organisation in the STEPS partnership and promotes civil and human rights for people with learning disabilities. Aspanias was founded in 1987, its main objectives being guardianship and pre-guardianship. It provides services and support for more than 150 men and women in the Barcelona region.

Guardianship, in all the possible ways stated by Law, is for people with learning disabilities who have no family or for whom their families are not in a position to provide support. Guardianship consists of covering the basic needs of the person, such as food, housing, employment and leisure, as well as protecting their interests and defending their rights. According to the principle of pre-guardianship, the foundation informs and advises families and professionals about related judicial and social issues, thus preparing the future for those who are likely to need a guardian in order to develop their lives.

The Aspronis group provides various health and day care services, training and work centres and residential services and special needs services for more than 500 service users in the Barcelona and Girona areas. The group was born in 1968 from a parents initiative. In order to meet the needs of disabled people in the region the group has enlarged and developed services, with a mission statement to fulfill the rights of people with disabilities and to provide services which improve the quality of their life.

The academic links in the Barcelona partnership are the School of Education Science, which is one of the five Schools of the University of Barcelona, and the Department of Research Methods and Diagnosis in Education.

The evaluation focus in the Barcelona partnership is on the development of civil rights for people with learning disabilities in daily life, looking towards practical recommendations.

2.3. PRODUCT 2 – DESCRIPTIVE QUESTIONS COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

This part of the comparative framework represents the primary element, being designed to capture and report on facets of policy and practice, service form and function and organisational and political context. Such factors define the characteristics and status of learning disability services nationally and across Europe. Similar approaches have been developed by other cross-national European comparisons in learning disability (Beadle-Brown et al, 2003). However, the IDRESNET project developed broad 'open' categories of description and comparison as opposed to descriptive reporting and analysis across a series of specific questions designed to focus on pre-identified facets of differentiation. In addition, the STEPS partners had the benefit of receiving local and national accounts presented at project conferences on factors such as organisational structures (for example, Cambridge, 2003), which could contribute to the analysis.

The following dimensions surfaced as key areas for cross-national comparison. Each is now examined in relation to the information provided by the different national partnerships and where helpful, wider evidence. A summary section under each (précis) offers key observations and conclusions.

2.3.1. DEVOLUTION OF RESPONSIBILITIES[1]

One of the most striking features of differentiation was variability in the relationship between central (national) governments and the local administration (local governments) and the resultant split in responsibilities for organising services for people with learning disabilities. This variability was represented along a continuum from centralised/national to devolved/local administrative and political systems.

In Sweden for example, the Lidingö services are the responsibility of the local municipality, largely in terms of influencing policies (although national frameworks exist) and almost entirely in terms of management and practice. They are consequently highly decentralised, with local accountability reinforced through the local administration of the municipality (Department of Elderly and Disabled) and the local Parliament, with the collection of local revenue for services via local taxation. The municipality is also charged with the dual roles of resource management and service development (for a full account of the system of organisation in Lidingö and its links with policy and the state, see Buzea, 2003).

This contrasts with Barcelona, where accountability is regionally located and determined by the autonomous community of Catalonia within Spain. Spain is divided into seventeen autonomous regions or communities, each having their own government and administration and full autonomy in health and social services. Catalonia is one such region, with Barcelona as its capital. In Spain, most services are provided by voluntary and parent organisations, which receive financial support from the administration of Catalonia via the municipalities. National social legislation (LISMI: Law for the social integration of people with disabilities) requires the provision of social services from both public and private sector organisations, but with a priority towards not-for-profit-organisations.

The Catalan administration is responsible for promoting social initiatives, user and carer participation and performance management. All social care functions are divided between national and regional (Catalan) levels, with the exception of a national pensions system. National policy in Spain supports family based services, which depend heavily on un-priced women's labour and which brings various social costs.

Arrangements in England are less decentralised, but the role of local government remains significant, mirroring aspects of the role of the municipality in Sweden, although of a larger scale in the volume, quantity and range of services, related activities and numbers of service users. The social services department of the Royal (London) Borough of Kensington and Chelsea is the lead agency for planning and organising community care locally (in partnership with relevant National Health Service trusts, namely

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[1] For cross reference please see section 4 – 8, product 2, questions 1, 3, 15 and 21

Kensington and Chelsea Primary Care Trust). However, NHS organisations unlike local government, are not elected by local people, so there is little local accountability and greater levels of centralised control by the Department of Health nationally. In England funds flow to the joint learning disability service from both central government tax revenue and from local council tax revenue. The statutory responsibilities of local government for service provision are dictated by central government, although decisions on priorities and how responsibilities are executed lies primarily with the local administration.

In the Netherlands there is also a relatively high level of decentralisation, with national law executed through local health care administrations, with scope for interpretation and a level of political freedom, with relatively less accountability to central government. Local government is also not directly involved as in the other countries, with national social security insurance (based on the national AWBZ, the national law for special health needs) providing the dominant source of funding for services for special health needs, including services for people with learning disabilities.

The German situation mirrors the English in many aspects. Health, social care and welfare legislation is in the hands of Federal Government, as it is with the UK Government. However the federal system in Germany gives greater scope to the states, including the City State of Hamburg, to develop regulations and legislation alongside the central providing role of the voluntary welfare sector. Funding relationships are similarly complex, with the majority of benefits for people with learning disabilities paid by tax financed social assistance (as in England) with district and city based offices in Hamburg. For example, in Hamburg the Ministry of Social Welfare and the Family is responsible for social insurance and assistance, but not for health insurance, pension insurance or unemployment insurance which are financed by employer and employee contributions. There is consequently a similar administrative differentiation of social care and welfare benefits and health care in Germany as in England.

Précis

Such differences reflect the evolution of different national and regional systems, contrasting levels of government, tiers of responsibility and lines of accountability. The status of national welfare systems proved a prominent feature of the relationship between central, federal, regional and local government, with forms of resource re-distribution often a product of this relationship. Although mixed systems of funding and accountability, as in England, Germany and Spain appeared more flexible, they also introduced greater confusion over responsibilities and appeared more complex organisationally and operationally, with the potential for greater fractures in accountability. Conversely, highly decentralised arrangements as in Sweden, appeared to provide for greater local accountability, transparency and scope for individualisation.

2.3.2. CARE MARKETS[2]

The impact of social care markets varied markedly across STEPS. The primary determinant was national policy, with widely polarised political and moral views on the role and potential of market economies in social care. A continuum between market models as in England, quasi-market or mixed economies of provision as in Germany and the Netherlands, to largely public or state lead and provided services as in Sweden was evident. However, there was invariably some degree of separation of funding responsibilities from those relating to service provision. This was achieved through a mixture of contracts, management or administrative walls between or within organisations and regulatory agencies or functions.

Following the 1990 community care reforms (Department of Health, 1989), market economies had developed in social care in England, with a range of different service providers evident in Kensington and Chelsea. However, it was observed that the market had largely failed to meet complex or expensive support needs and required careful management through joint partnership commissioning from social services and health. Core contracts with service providers are set, with individual needs also identified contractually, with individual review and performance monitoring.

A policy shift towards market models is developing in Hamburg, despite an overall lack of market conviction on the part of key players. Market development is also restrained by the powerful voluntary welfare sector, with the state covering costs. A framework contract between the Hamburg Ministry of Social Welfare and the Family stipulates funding levels and costs, articulated through service agreements with different provider organisations. However, the basis is a prospective payment system, with the inefficiencies and rigidity this was seen to generate.

The emergence of parent led organisations in Rotterdam has aided the development of a mixed economy, with diversification in the supply of services through parent led initiatives in housing and support. The internal markets of the big service providers, with specialisation across service types, has also led to managed competition, as service users have the capacity to switch between providers, with funds following them. Overall however, service agreements predominate over competition, with care providers setting annual targets in liaison with the local care office and with performance monitored and funds released accordingly. There is consequently a separation of purchasing from providing, contrasting with arrangements in Sweden where there is no such separation.

In Lidingö, a management wall exists between the functions of financing and budgeting and service delivery, primarily through the administration of planning and needs assessment processes, with services highly individualised. Under such arrangements a social care market is deemed unnecessary.

In Barcelona a number of public sector, not-for-profit and private sector providers operate within a limited mixed economy, with some service providers diversifying provision, although with services for some special needs groups remaining extremely limited. Several regions, including Catalonia, are however, proposing a separation of purchasing from providing through a quasi-market system mirroring arrangements in England.

Précis
Quasi-market approaches appear to offer potential for affecting changes in the balance and pattern of services where large scale or congregate provisions exist compared to arrangements where services are already highly individualised. It was also recognised across STEPS that the choices service users and administrations have when contracting or arranging for individual services are improved with mixed state and independent sector provision, with a directional drift towards social care markets seeming to emerge. However, the risk of service users being excluded from market relationships was also recognised (Cambridge and Brown, 1997) and in Kensington and Chelsea much effort had been invested in user representation in purchasing and inspection. Structural rigidities and resistance from dominant interests such as large providing organisations seemed to be holding back such changes in some instances.

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[2] For cross reference please see section 4 – 8, product 2, question 14

2.3.3. INTER-AGENCY WORKING[3]

Joint or inter-agency relationships varied widely across STEPS, largely determined by the policy backcloth to services and macro-organisation factors such as the relative integration of social care, health care, education and housing services. In Sweden, inter-agency co-operation was primarily determined by the needs of individuals and in England by the separation of different functions within local government and the NHS. For example, joint learning disability service management and budgeting between health and social services was essential, alongside co-ordination with education and housing services.

In the Netherlands, inter-agency working was less relevant and has tended to develop on a voluntary-reactive basis in Rotterdam. Such a permissive approach is also still evident in Hamburg and due to the complex service system in Germany inter-agency working is deemed to be necessary. In order to grant benefits easily and quickly the different 'rehabilitation agencies' have a statutory obligation to establish a joint service office for advice and support (see section 4, product 2, question 21). In Hamburg, service offices are established, but in practice remain poorly integrated and lack influence in the service system. Joint working between the various administrations remains in its infancy, although the Ministry co-operates with the provider organisations in contract commissioning and in the development of pilot projects.

Linked to the development or otherwise of a mixed economy of provision or social care market, the status of service providing organisations in the respective national contexts and local partnerships varied, although some patterns emerged. Without a market and with direct public provision, there was no voluntary sector in Sweden. Conversely, with a managed and relatively rigid mixed economy of providing, voluntary providers dominated in the Netherlands. Only in areas and activities where there were no voluntary organisations, was direct public provision through government initiatives seen. A similar picture emerged in Germany, where the most important service providing organisations belong to the voluntary sector, many with roots as religious foundations. In England there were a number of national organisations delivering services for people with learning disabilities, many of which also had a campaigning role. Locally, there were also organisations involved in providing services such as advocacy. In Catalonia, co-operation between service providers and the local administration was minimal, despite providers being resource dependent on the administration. Complex administrative systems also inhibited collaboration between local municipalities and the Catalan administration, despite a legal imperative for joint working.

Précis
To varying extent, all STEPS partners worked with separate service providing organisations, although their status and independence from the public sector varied. In both public dominated and quasi-market conditions service providers required transparent relationships with their local administrations for the planning and funding of services. The scope for voluntary or not-for-profit providers to emerge appeared more restricted in public dominated systems than those where there was a mixed economy or market. Overall, there was seen to be a need to diversify the supply of services, which was often perceived as rigid due to institutionalised purchasing arrangements. In some national contexts there was little need for joint working as responsibilities were clearly demarcated, whereas in others this was of critical importance for integrated community care. As community care develops the need for an increasing emphasis on inter-agency and inter-professional working was recognised across STEPS.

2.3.4. SERVICE PLANNING AND DEVELOPMENT[4]

Arrangements and responsibilities for the planning and development activities undertaken within each partnership varied according to the extent, direction and influence of national, federal and local policy frameworks. Planning also ranged between formal top-down arrangements to those centred on service

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[3] For cross reference please see section 4 – 8, product 2, question 4
[4] For cross reference please see section 4 – 8, product 2, questions 1, 2 and 15

users, with different forms of individual service planning employed. An overall tension between strategic service planning and individual service planning surfaced.

Strategic planning and development is a function of the municipality in Sweden, driven by a process matching resources to individual needs. A request for a service from the person or their representative leads to resource negotiation. 'Seasonal meetings' as a method of individual planning in Lidingö are similar to person-centred planning in England (Department of Health, 2001). With more explicit mixed economies or care markets in the other partnerships, there tended to be more formal and hierarchical planning processes, generally involving a range of local interests.

In Rotterdam, as elsewhere in the Netherlands, care providers set annual performance targets with the care office. These are monitored, with funds allocated according to both performance and numbers. An advisory body comprising the main stakeholders (carers, service users and parents) also inputs into the planning process. Planning in Hamburg is primarily articulated through service agreements between the Ministry and service providers, based on the number of service users and costs. As in Rotterdam, there is also a legal requirement for a service plan for each user, developed by the social assistance body responsible, with the capacity for other interests to be included in the process according to the preferences of the user. Most providers develop their own in house planning systems – using service conferences in the case in the partnership. There are however often fractures between strategic and individual service planning as a consequence.

Social service legislation in Spain empowers municipalities to manage primary health and social services and some specialised services. The region is responsible for most specialised services for people with disabilities – in Catalonia, municipalities are required to collaborate on service planning and development with the Catalan administration. All services are also obliged to undertake person-centred plans of intervention which are conducted by a multi-professional team in order to promote integrated service provision. Individual plans include objectives and goals and are professionally monitored but do not place the person at the centre of decision-making.

In England, community care planning involving a range of stakeholders following the 1990 community care reforms (Department of Health, 1989) had developed into Joint Investment Plans since the introduction of partnership working. Person-centred planning (PCP) is a requirement of Valuing People (Department of Health, 2001) and is currently being introduced nationally. Care management, as responsibility of local authorities has the potential to link strategic and person-centred planning but this has proved difficult (Cambridge, 1999b). In Kensington and Chelsea, person-centred plans are aggregated to inform service commissioning.

Précis
Individual service planning was a major feature of all STEPS partnerships, underpinning service planning and development at the macro-level. Although very different arrangements were being employed, largely determined by local and national responsibilities for learning disability services, an information and action gap between strategic planning at regional or authority levels and tactical planning at individual or case levels existed. Management information systems on individual service costs and needs are consequently required to link the two systems but were largely underdeveloped. More inclusive stakeholder or constituency planning systems were beginning to emerge across STEPS and break the mould of traditional or institutionalised power relations between commissioners and providers of services.

2.3.5. ACCESS AND ELIGIBILITY[5]

Eligibility is a key criterion for comparing learning disability service arrangements and as pointed out by Beadle-Brown et al (2003) and reinforced by Weinbach (2004), the various terminologies adopted for 'learning disability' in the STEPS context or 'intellectual disability' in the IDRESNET context, complicate any analysis:

> *'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.'* (Beadle-Brown et al, 2003, p. 2)

Beadle-Brown et al (2003) observes:

- in all the countries people with learning disabilities have the same rights as other citizens

- access to rights is limited by service configurations, such as institutionalised and congregate models

- in most countries there are eligibility criteria which help determine access and a right to services, and

- access to services is often determined by relative availability or scarcity, rather than eligibility per se

Approaches to eligibility were seen to fall into three main groups (Beadle-Brown et al, 2003):

- functional limitations (such as the need for housing, work or support)

- the nature of disability (such as whether the person has been assessed to have a learning disability)

- the social insurance status of the individual (whether they are eligible for benefits or insurance payments)

The above observations apply also to STEPS, although a forth category surfaced, namely the targeting criteria used by services. This may be set according to a particular level of assessed need (vertical targeting), but can also vary between authorities or administrations (horizontal targeting). This aspect proved very important across STEPS because it related directly to issues of equality and equity in the context of territorial justice and target efficiency (Davies and Challis, 1986).

There is no legal right to services in England, with local authority social services departments determining access from a process of individual needs assessments and matching resources to needs (in Kensington

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[5] For cross reference please see section 4 – 8, product 2, question 5

and Chelsea this is a psychological assessment using a range of criteria). This approach creates potential inequities between local authorities. However Valuing People (Department of Health, 2001) offers a definition of disability as being identified in the early years. There were generally clearer national eligibility criteria operating across the other STEPS partners, primarily based on level of disability and determined through assessment within one or more of the groups outlined above.

In Germany, benefit entitlement is afforded to persons defined as disabled according to the World Health Organisation definition, with permanent participation in society restricted, and through medical determination. For people with severe disabilities entitlement to various protection and benefits, their level of disability must be at least 50%, as determined by the local administration.

No common definitions for learning disability are utilised in Catalonia or Spain. The ICD-10 classification and AAMR-1992 criteria are widely used (Salvador-Carulla et al, 2003). There exists a list for grading all disabilities according to the degree of disability and an index of severity. Whilst health care is an entitlement, social care is discretionary. A certificate of disability is required to gain access to specialised services provided by the Catalan administration. This specifies the type and degree of disability. Assessed disability has to be at 65% or above to qualify for services. Following assessment, the administration offers a service. If refused, the only option is to seek self-financed private sector provision. The service provider can also accept or refuse provision to the service user proposed by the administration. User choice is consequently very limited.

User choice in the Dutch system is between a limited number of service providers. The system in the Netherlands stipulates eligibility at national statutory level through a legal framework enacted by local health care administrations and representing a legal right to services. Consequently, formulations are provided independently of provider organisations and local government on the basis of IQ tests and clinical observations (Vlaskamp and Poppes, 2003).

The citizen perspective developed in Sweden, along with experience with de-institutionalisation (Mansell and Ericsson, 1996) means that if a person with a disability experiences difficulties managing their everyday life, then they are eligible for support if requested. The dual criteria of disability and ability to manage daily life therefore apply.

Précis

The various eligibility arrangements across STEPS are products of different cultural and legal traditions and in some cases historical practices. Whether eligibility was stipulated or whatever criteria were used, the most important consideration appears to be access routes and forms of assessment. Eligibility alone did not ensure an appropriate service of an acceptable quality, as organisational, finding or institutional barriers also operated. The predominance of providers or care markets proved influential for access in some national situations. The potential for explicit targeting criteria to help match resources to needs and ensure equitable provision was evident, particularly at a time resource constraints were increasingly influencing service management across STEPS.

2.3.6.   SERVICE MODELS, MAINSTREAMING AND INTEGRATION[6]

The degree of segregation of learning disability services from mainstream provisions or the community varied significantly across STEPS, largely reflecting differential progress with de-institutionalisation and the development of community care, the influence of normalisation and related principles (Nirje, 1992; O'Brien, 1987; Wolfensberger, 1972 and 1992) and the service models predominating in the community. Such variation is particularly marked between Britain and Scandinavia on the one hand and western and southern Europe on the other, for cultural and historical reasons (Ericsson and Mansell, 1996) and was also noted across IDRESNET (Beadle-Brown et al, 2003). With national differences also due to

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[6] For cross reference please see section 4 – 8, product 2, questions 6 and 7

structural and policy factors, the respective national and local experiences do not reflect comparative measures of success, rather the reaching of different points on different but sometimes parallel journeys.

Close to the destination of total de-institutionalisation lies Sweden, where the approach to community support is highly individualised, led by the premise that the task is to offer and enable as normal a life as possible for the person with a learning disability, compared to the lives of other members of the community and informed by citizenship. Services are consequently highly individualised, localised and community based, with more formal services such as employment projects designed to enable individual objectives to be met. There is also equal access to welfare services offered by society to all citizens (Ericsson 2003a and 2003b).

This contrasts markedly with Spain, where services tend to be more formally constructed, congregate and separate in their form and function. It could be interpreted that services in Barcelona and Catalonia are in an earlier phase of de-institutionalisation than elsewhere across STEPS, although since 1985 there has been a shift from institutional to community care. Social services in Barcelona are operated by the municipality, which offers housing, limited residential care, technical advice and meals. Specialised social services are operated by the Catalonian administration and include employment, early intervention, specialised housing assessment and residential care. There are consequently split responsibilities. Most service providing organisations have evolved from parent led or Catholic (church) organisations, mirroring experience in Hamburg and Germany, where many large service providing organisations have Protestant (church) origins.

Some effort is currently being made in Germany to dilute the dominance of the large service providing organisations in the development of community integrated services. A push for greater integration is underpinned by statute, which promotes the integration and participation of disabled people in society, although experience as elsewhere suggests an implementation gap between strategic policy and practice. For instance in Hamburg, pedagogical assistance in people's own homes (pbw) is in practice restricted to people with mild learning disabilities, reflecting funding restrictions. Hence, many people with more severe learning disabilities remain segregated in more institutionalised services, although small demonstration housing and employment projects for community care for the most disabled are being developed.

In the Netherlands and England, individual service planning systems developed outside service providing are leading to more individualised service packages. In Rotterdam resources come to providing organisations based on the number of people using the service, although are now being linked to levels of need by individual costs, helping overcome disincentives to provide for people with complex or expensive support needs. Many day centres are not accessible for people with complex needs and when people with milder learning disabilities move to community care, people with profound or multiple disabilities tend to take their place, reflecting institutionalised segregation within services.

Similar disincentives and constrains are experienced in Kensington and Chelsea with the management of imperfect care markets. Some needs have to be met by purchasing services outside the borough (approximately 25%), with no specialist services for challenging behaviour or autism available locally. However, the multi-disciplinary community learning disability team provides support to staff and carers, including parents for service users with challenging behaviours in various community settings, providing integrated support. The ongoing shift to community care through models such as independent and supported living and the use of person-centred planning and direct payments suggests that services are becoming increasingly individualised and community located. This trend towards personal funding is reflected elsewhere. The Dutch system of personal budgets and individual planning is developing rapidly and having more impact on services than in England.

Précis

There was a general consensus on the need for ongoing de-institutionalisation – towards individual services and community based care and away from congregate provisions – although different STEPS partners were at different stages of the journey. Direct payments or individual budgets were widely viewed as an important vehicle for helping achieve structural change and were being widely developed in the Dutch, German and English systems. It was also recognised that specialist services for people with complex or additional needs required wider development through mainstream competence (Mansell, 1993). Multi-disciplinary community teams offered a device achieving greater integration, although financial and organisational disincentives in some national and local systems remain to be tackled if individualisation and choice are to be further progressed.

2.3.7. NATIONAL POLICIES[7]

A high level of policy differentiation existed between social policy, generic disability and learning disability policy across STEPS. The impact and relevance of family policy, citizenship and policies relating to the community also contrasted. The relationships between primary policy spheres such as health, education and social care and the impact of specific anti-discrimination policy and equality legislation also varied markedly. This complexity reflects historical, cultural and legal differences, such as the influence of de-institutionalisation in England and Sweden and respective welfare traditions.

Beadle-Brown et al (2003, p. 5) identified four primary factors helping explain such differences:

- the history and pattern of development of learning 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.' (Beadle-Brown et al, 2003, p. 5)

Such factors can be termed macro-determinants and in the experience of STEPS, four additional factors proved influential:

- relationships between central and local government and the degree of political devolution

- the status and profile of learning disability policy within the wider social policy realm

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[7] For cross reference please see section 4 – 8, product 2, questions 10 and 22

- the development of mixed economies or markets and the nature of the separation between purchasing and providing

- the impact of anti-discrimination, equality and human rights legislation in the disability and learning disability fields

Beadle-Brown et al (2003) note that the development of policy in social care and learning disability in Britain lacks a strong evidence base, as opposed to say Sweden, where there is a tradition of empirically led policy development as well as strong ideological influences. In Britain learning disability policy was led by generic community care policy until the recent introduction of a national learning disability framework (Department of Health, 2001). In Germany and the Netherlands the power of the service providing institutions – long established organisations, often borne from religious institutions (Schädler et al, 2003) – is influential in policy implementation. In the Netherlands there is a tradition of waiting lists for entry into some services (Vlaskamp and Poppes, 2003, p. 93). In Spain and Catalonia the recent regional autonomy and the tradition of the family and local community are influential factors. In Britain and Germany the tension between central and local government continues to exert and influence on policy and practice.

The German federal law and related social code determines social welfare and insurance, with a social code also determining the integration and rehabilitation of people with disabilities. Within the framework of national law, each state has developed and implemented its own regulations. There is a federal equality act relating to anti-discrimination for people with disabilities, with plans for the Hamburg Senate to pass the Hamburg equality law in 2004.

In England the relationship between the national and local state is determined by a range of statutes, legal directives and court rulings. In Kensington and Chelsea the primary care trust is directly accountable to the Department of Health. Under Valuing People, each local authority is monitored on the services provided, with resources made available annually through the Learning Disability Development Fund. There are also various statutes to outlaw discrimination or support public bodies in promoting anti-discrimination, with disability specifically referenced. Acts of Parliament cover sex, race, disability and homosexual/
religious discrimination as well as human rights more broadly.

In the Netherlands the impact of central government on the care and support of people with learning disabilities is relatively minor and indirect, with funding to local Care Offices. By law, budgets apply to both residential and non-residential facilities, with the amount of money allocated to this budget related to the number of service users. With a few exceptions, levels of funding are identical, with the service responsible for redistribution (Vlaskamp, 1999). Specific initiatives such as Verstandig Veranderen (Sensible Change) promote client oriented budgets and a long term plan (De Perken te buiten (Outside the Pale) states that people with learning disabilities are citizens with the same opportunities and choices as other people, entitled to support in executing their rights (Vlaskamp and Poppes, 2003). In this context community care is being promoted, with disincentives for large institutional provisions and the introduction of supported living (Vlaskamp, 1999).

Swedish social policy is underpinned by citizenship and learning disability policy by normalisation and social role valorisation, reflected in relatively early de-institutionalisation and successive acts of parliament gradually introducing community based services and an ordinary life for people with learning disabilities (Ericsson, 2003a). The local administration (municipality) has a relatively high level of freedom to use the taxes decided upon and collected by the local Parliament, within a framework of national regulations.

National policy in Spain gives a priority to family and community support for people with disabilities in the context of the National Action Plans for people with disabilities and for social inclusion. Regional plans also exist for some services or needs groups. People with learning disabilities have the same civil rights as other Spanish citizens and the Spanish law for the social integration of people with disabilities

provides a framework for policy, the main objectives being normalisation and community care. Legislation lies midway 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 (Salvador-Carulla et al, 2003).

In Britain the legacy of market policies in social and health care are having a lasting impact, with the relative reduction of national and local state responsibilities and the privatisation of collective and state assets impacting on the nature and provision of social care services for people with learning disabilities (Cambridge and Brown, 1997). A new cycle of regulation with national inspections and care standards, best value and quality concerns is now being articulated. Rapid and frequent policy change has characterised English social policy, destabilising service management practice and suggesting the need for both policy demonstration initiatives and greater continuity in social policy.

All STEPS partners were influenced by EU legislation and directives on anti-discrimination and human rights, impacting variably upon national legislation, with member states at various stages of transposing such legislation into national law[8].

Précis

Lessons for policy development and implementation are evident from STEPS. National policy frameworks are important for directional guidance but also require flexibility to respond to local or regional needs – less relevant to decentralised arrangements as in Sweden than to more centralised arrangement as in England, with the German federal system mid-way along this continuum. There is evidence of a need for policy demonstration and evaluation to help bridge the different implementation gaps experienced between national policy and local practice. Policy formulation also needs to attend to rigid national and local funding systems if de-institutionalisation in its widest sense is to progress and the widely shared goals of individualisation and person-centred services are to be promoted. There was also a risk that policy could become trapped in cycles of deregulation-regulation from political ideology rather than change being focused more directly on the quality of services provided to people with learning disabilities or their effective participation.

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[8] The EU-website provides an overview on EU-legislation and transposing of the EU-directives in national law. http://europa.eu.int/comm/employment_social/fundamental_rights/index_en.htm

2.3.8. ADVOCACY AND INVOLVEMENT[9]

Advocacy, user representation and complaints represent important instruments for aiding the empowerment and participation of people with learning disabilities and their carers. Various approaches to advocacy (Cambridge and Williams, 2004) exist alongside formal checks and balances such as complaints procedures operated by services themselves or by local administrations. At the highest national levels, Ombudsman services and national and European law provides safeguards for protecting and promoting the rights of service users and citizens.

In Barcelona an Office for non-discrimination informs, educates and raises awareness on matters relating to equality and rights, acting as mediators in complaints about discrimination. There is also a national Ombudsman in Spain. In cases where a court judge considers that the person does not have capacity to consent, the guardianship law makes it possible to protect people under a guardianship of an individual or an organisation.

In Germany, advocacy councils for people with learning disabilities have been established to work with administrations in some states (although not yet Hamburg), with statutory advisory boards representing user interests in residential services and sheltered workshops. User groups such as People First, the Strong Angels, the Association for Blind People and Autonomous Living (Autonom Leben e.V.) are prominent and provide advice, support activities and political lobbying. Parent's groups currently have greater influence however. Examples include Living with Disabilities (Leben mit Behinderung e.V.) and Parents for Integration (Landesarbeitsgemeinschaft Eltern für Integration e.V), which have also developed as service providers. A strong parent's movement has fought for integration from kindergarten, through schools to employment. Legal guardians are obliged to strengthen the self-determination of people with learning disabilities through involvement in decision-making processes.

The German social code provides for diverse legal appeal procedures. At the state level in Hamburg, the co-ordinator (comparable to an Ombudsman) for the equality of people with learning disabilities investigates complaints and there is also a legal right to challenge services under federal law for individuals or organisations. Service providers have their own complaints processes managed, for example, by 'complaints representatives'. Compared to England, the relative power of user and parent's organisations is reversed – Kensington and Chelsea facilitate a user forum, users act as consultants for service audit and inspection and are involved in staff interviews. User representation on the local partnership board represents formal involvement, whereas in Hamburg and Germany involvement is predominantly informal.

In England, national self-advocacy organisations like People First are locally and nationally prominent. In Kensington and Chelsea Equal People, a local group of MENCAP, Quality Network with BILD (British Institute of Learning Disabilities) and the local advocacy alliance where care managers and service users can access citizen advocacy, are examples. Although parent organisations are less prominent, Kensington and Chelsea work with a parent's group for younger people with learning disabilities (Full of Life), there is a parent's and carer's forum and parent's representatives are active on the partnership board. Carers as well as people with learning disabilities have access to needs assessment and there is a carer's grant available from central government.

A hierarchy of complaints procedures exists in England, partly reflecting the fragmentation of responsibilities across social care markets (Cambridge and Brown, 1997) and the spread of responsibilities across agencies. The director of social services manages complaints relating to the local administration. The NHS and primary care trusts also have their own in-house complaints procedures. In Sweden, if negotiation about services between the administration and the person or their representative breaks down, a complaint can be lodged to the national Judicial Ombudsman if there are legal issues or to the national Disability Ombudsman, who will make a judgement based on human and disability rights issues. Decisions are binding in both cases (Lööw, 2003). England, Germany and the Netherlands also have

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[9] For cross reference please see section – 8, product 2, questions 8, 9, 19 and 20

Ombudsman services modelled on the Swedish experience (European Commission 2002). In England, issues of mal-administration in local government can be referred to the national office of the Local Government Ombudsman and in the Netherlands the National Ombudsman deals with complaints from members of the public concerning mal-administration by public bodies and officials. Arrangements reflect local configurations of interest – in the Netherlands for example, the Ombudsman would never give advice or make a decision without consulting with the Federation of Parent's Organisations.

In Sweden and Lidingö the tradition of community and family involvement means that families are routinely involved in service and support decisions, but also that some families are involved in parent's organisations to additionally work at a general level with disability and community issues. However, if negotiations break down the person and their representative has the initial possibility of lodging a complaint with the administration of the disability service, directly to the political board or to the provincial administration.

In the Netherlands and Germany advocacy is largely individual or through parent's organisations. Self-advocacy in the Netherlands is promoted primarily through specific self-advocacy organisations such as Onderling Sterk and secondarily through social groups such as Circles of Friends, aiming to develop social networks and skills. Parent's and families are themselves supported by social workers and parental input is facilitated by representation on the boards of services. Locally, service providers utilise protocols for managing complaints. For example, when there are disagreements experts are called upon to help resolve or provide advice. Practice in provider organisations and more widely in the Netherlands is underpinned by ethics committees, which unlike in England where they function primarily in relation to research, are frequently used to resolve moral dilemmas, conflicts of interest or practice disputes (Meininger, 2002).

Précis

User, carer and parental involvement and approaches to advocacy vary across STEPS according to cultural factors and rights traditions. With advocacy arrangements diverse, each partner had developed a particularly bias, such as parent advocacy in Germany, self-advocacy in England and citizen advocacy in Sweden. Most partners operated local complaints procedures, generally located within services or administrations, risking compromised objectivity. However, most also had access to higher levels of complaints, could mount challenges via legal or judicial routes or enjoyed variations of the Ombudsman model. In institutionalised arrangements, advocacy appeared essential to break down the power of administrations or service providers and to open up services to public scrutiny. In individual arrangements, advocacy appeared essential to maintain the influence of the user voice. It is evident that advocacy needs to operate at both levels if power is to be effectively shifted from bureaucratic and professional interests to service users.

2.3.9. REGULATION AND INSPECTION[10]

Arrangements for regulation largely reflected organisational relationships between public and funding bodies and service providers. With regulation determined by performance and market management in England, underpinned by national service standards and inspections, a number of national and local bodies work in combination. In Hamburg arrangements for quality assurance and inspection are agreed through the Hamburg framework contract with details of the process and outputs required, a quality standard and internal and external quality assurance and reporting (for example benchmarking and EFQM – European Foundation for Quality Management).

Local inspection and registration functions for services in England have recently been replaced by national care standards and inspection by the Commission for Social Care Inspection, with the Social Care Institute for Excellence and the Commission for Health Improvement also having national remits, along with the Audit Commission, able to inspect local government services and the Social Services Inspectorate, able to inspect local authority social services departments and the services they commission. Three star authorities (such as the Royal Borough of Kensington and Chelsea) are not audited as regularly as others as their performance is deemed to be excellent. Regular monitoring by residential placements officers of people in residential and nursing homes takes place and in the local authority senior managers and care managers visit services and the Quality Network involves service users in inspecting services.

Elsewhere inspection and complaints functions merge. In the Netherlands care providers set basic performance and production targets with the local Care Office. Monitoring is through Client Boards, where parents and relatives are represented and which can signal to central government (as can other care providers) through its Health Inspection function. In Sweden the ways services are constructed, funded and reviewed reduces the need for formal inspection processes, but services provided through the municipality can be inspected by the provincial administration.

Residential services in Spain have mechanisms to support the participation of people with disabilities. Primary regulation is at both regional (Catalan) level and local (municipality) level with minimum standards, registration and inspection of services for people with disabilities. The Catalan government has its own inspection with its own service standards. Inspection is both planned (routine) and random and can also react to complaints made by service users, families or the representatives of service users.

Précis
Regulation and inspection across STEPS tends to be polarised between nationally determined and locally initiated arrangements, the latter often being permissive. Links exist with complaints procedures and regulation is often tied to funding and accountability, reflecting purchasing or contractual relationships. Overall, market systems wee seen to require more elaborate monitoring and regulation than public systems. Balanced systems of regulation are required, where local arrangements for inspection are developed in the context of national or regional frameworks for quality assurance. In all cases a priority for assessment and measurement was recognised as being user outcomes. It was also evident that quality inspection should be an integral part of funding and service planning arrangements as well as purchasing and commissioning more widely.

2.3.10. COST MANAGEMENT ARRANGEMENTS[11]

Much of the experience with cost management across STEPS was determined by the relationships between national and local systems, the extent to which there was a mixed economy of provision or care market and the impact of national or local funding requirements. Direct payments or personal budgets were developing in a variety of organisational and policy contexts and were widely seen as an instrument for de-institutionalisation and promoting user choice. Conversely, prospective payment systems were

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[10] For cross reference please see section 4 – 8, product 2, question 16

[11] For cross reference please see section 4 – 8, product 2, questions 11, 17, 18 and 21

also dominant in shaping and maintain patterns of service provision in some partners, representing relatively institutionalised and inflexible purchasing, although not necessarily mutually exclusive of individualised systems of funding or cost management.

Overall, a policy interest in cost-effectiveness was developing in response to increasingly constrained funding environments. Beadle-Brown et al (2003), examining the person-centred-ness of funding, observed a shift in the UK from block purchasing to individual planning and contracts and an established high level of person-centred-ness in Sweden. Germany, the Netherlands and Sweden were also seen as countries where people had a right to services, with funding generally on the basis of individual entitlement. In Spain, funding was seen as primarily discretionary, while in England there was a mixture of the two approaches.

In Sweden, with services highly individualised and funded, there was a good understanding of the relationships between individual needs and resources, with accountability to the municipality and local parliament reinforcing transparency and openness. There was also a level of individualised funding in as much as people needing personal assistance received a sum related to their support needs to use for employing personal assistants, representing an individual flexi-budget for a particular service component. At a policy level, quality is considered important and it is accepted that community services are overall more cost-effective than institutionalised provisions. Due to the high degree of financial autonomy enjoyed by the municipalities, only occasionally in Sweden is economic support channelled from national to local levels.

In Catalonia the regional government manages the costs of services through an arrangement specifying maximum and minimum costs. A prospective payment system operates as in Germany and the Netherlands, whereby providers charge and are paid, according to the number of service users, with costs unadjusted to individual needs or service utilisation. It is intended to shift funding in Catalonia to a contract based system. There is currently no provision for direct payments in Spain.

In the Netherlands, the allocation of funds to local learning disability service providers is determined by the number of users at fixed per capita rates, with the exception of some expensive and complex needs. Budgets are allocated by the local Care Office (Zorgkantoor), accountable to the relevant central government ministry and financed by special health insurance (AWBZ). There is consequently little notion of individual costs, although the introduction of personal budgets is breaking down this structural rigidity, as they are currently received by around 20% of people with learning disabilities. Since 2003 all new applications for personal budgets are considered on a strictly individual basis, similar to the needs assessments in Britain. The Dutch government has fixed a ceiling to both systems of funding, although it is widely recognised that the shift to personal budgets will lead to more effective resource allocation, despite various bureaucratic disincentives to obtaining them.

In England local authority social service departments, usually in partnership with primary care trusts, hold information on individual needs from assessments and as purchasers of services, on individual costs. In Kensington and Chelsea this information is held on IT systems, facilitating cost aggregation for different services or individual service users. With statutory backing, the direct payments scheme has advanced, with national guidelines from central government (Department of Health, 1996). Sources of funding are mixed, with the UK government funding local authorities to deliver services using a formula based on past performance and demographic data. Ring-fenced grants are also available for particular services or service groups. Some local revenue is collected through council tax, although arrangements are less localised than in Sweden.

Services are purchased by the Partnership Board through contracts with a range of providers, utilising joint investment plans and underpinned by contract monitoring and individual service review. Much is consequently understood about the relationships between individual and aggregate resources and needs and the per capita costs and benefits of different services. Nationally it is understood that although community care for people with learning disabilities is generally more expensive than institutional care, it is also more cost-effective (Cambridge et al, 2002).

In Germany, most benefits for people with learning disabilities are funded through the tax-financed Social Assistance. In cases where people are entitled to welfare insurance benefits, then services are financed by this source. Funding in Germany is structurally divided between residential and non-residential or community services, reflecting a relatively rigid supply led system, with residential care financed through prospective payments. The Hamburg Ministry for Social Welfare and Family agrees performance targets and cost-payments in advance of service delivery and whilst this enables the institutions or service providing organisations to redistribute resources according to needs, there remain disincentives to provide support for people with expensive or complex needs, despite costs being determined according to different needs groups and variation within groups and across individuals over time. The system represents financial predictability and security for the residential care sector but discourages innovation and individualisation, with costs tending to increase over time and disadvantages for user choice apparent.

Community integrated services, such as pedagogical assistance in people's own home (pbw), are funded on an hourly per capita basis, although in Hamburg this option is restricted by a low average of 7 to 8 hours per week. The intention is to promote rehabilitation by reducing hours over time as independence increases. There is consequently more understanding of cost-effectiveness than with residential provision. Although a legal priority exists for the development of community integrated services with a process of modernisation initiated through market reforms (Schädler et al, 2003), shifts in the pattern of services away from residential care are proving difficult. For example, in Hamburg around 90% of funds are still trapped in residential care with a consequential impact on the availability of pedagogic assistance. Personal budgets are currently being piloted in Hamburg but have had limited success due to limited service options and choices.

Précis

With the imperative to develop open and accountable systems of funding, the overall direction of change across STEPS is towards individualised funding systems and transparent individual service costings, helping ongoing de-institutionalisation, the break-up of local or state monopolies in supply led provision and the dilution of the power of service providing organisations. Investment in such change should provide a good foundation for the continued development and extension of personal budgets across STEPS. In parallel, effective IT cost information systems were required for accessible cost management. Checks and balances were also required for personal budgets to protect service users, safeguard accountability for public funds (Cambridge and Brown, 1997) and remove disincentives for individualised funding.

2.3.11. STAFF DEVELOPMENT AND TRAINING[12]

There was little demand for formal policy on staff training and development in Sweden due to the ways services are constructed, compared to England, where a care market operated. With provision informed by normalisation and the right for an ordinary life in the community, there are no national or local requirements for education or qualifications and consequently no formal programmes for staff training. Staff development was determined by needs and opportunities, with staff conferences organised to facilitate the discussion, dissemination and exchange of ideas and best practice.

This appears diametrically opposed to policy in Britain, reflected in a shift to increased regulation, alongside explicit workforce development goals in social care designed to address the legacy of a relatively low paid, inexperienced and poorly qualified workforce. Valuing People set a workforce development target for 2005 of 50% of the social care workforce having National Vocational Qualifications (level 2), with similar management requirements to level 4, to be monitored through care standards inspections and a national training organisation for social care. Professionals working in social care enjoy their own codes of conduct and accreditation through their professional bodies.

In comparison, in Rotterdam, levels of staff training and qualification are extremely high, with over half of employees having degree level qualifications in the social sciences. Consequently, current staff

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[12] For cross reference please see section 4 – 8, product 2, question 12 and 13

development priorities cover areas such as network development skills and community care as services become increasingly located in community settings. A similar backcloth exists in Germany, where long standing requirements determine staff qualifications. Professional training programmes exist at national level for the different professions in health and social care (e.g. nursing and social work) with degree level qualifications for social pedagogues, care management, health management and so on. National regulations determine the type and level of training required with the consequence that practice competence is found in set categories rather than a multi-disciplinary context, with theory often lagging behind practice innovation.

Précis

Respective advantages and disadvantages are evident in highly regulated, top-down and relatively informal or responsive arrangements. Each STEPS partnership was addressing staff development in very different ways in response to varying management, practice and resource demands. Whilst some were professionally dominated, others were competence based or led by national policy. However, staff development which prioritised practice competence, experiential learning, reflective practice and innovation were evidently well placed to progress integrated community care and multi-disciplinary working.

SECTION 3. OBSERVATIONS AND CONCLUSIONS

3.1. SUMMARY COMPARISONS

Much of the difficulty in comparing arrangements in learning disability services across STEPS, reflected variation in the relationships between a series of key domains:

- generic disability services and specialist learning disability services

- health care, social care and community care

- hierarchies of central, regional and local government

- devolved power and responsibilities regionally and locally

- revenue collection and flows of funds from national to local levels

- national policy and legal frameworks

- public administration and service providing

Such over-arching differences are important when considering re-organising or further de-institutionalising services, but do not seem to be reflected in the extent to which there is community inclusion or the integration for people with learning disabilities. Such important considerations seemed to depend as much on intervening variables such as culture, values and the action of local managers and practitioners, than on major structural or organisational conditions.

The relationship between the management and organisation of generic disability services and specialist learning disability services in social or community care varied widely across STEPS. Variation was evident in the relationship between the partnerships and higher-level public or political bodies across the continuum from local administrations to city/federal state government, regional government and national (central) government. Variation was also evident between generic disability and specialist learning disability policy and practice. In Rotterdam and Hamburg the main emphasis is towards a generic disability approach, while in Kensington and Chelsea, learning disability services form a largely separate strand of social care policy, practice and service organisation, both within the local authority social services department and the partner NHS trust. In the Dutch and German contexts, specialist workers and professionals support people with learning disabilities but from more generic institutional or providing structures. In Barcelona mainstream primary services are provided locally, while specialised services for people with disabilities are separately financed and organised by the Catalan regional authority.

In the London system, purchasing (by the Learning Disability Partnership Board) is separated from providing (by the social service department, primary care trust and more significantly by various voluntary, not-for-profit and private agencies within and outside Kensington and Chelsea), with contracts defining the basis of such relationships. In Hamburg purchasing (by the Ministry) is also separated from providing by the voluntary welfare organisations, but the nature of the purchasing provider relationship and the processes operating are different, representing the pre-market 'service agreements' previously operating in English context.

Also of significance across STEPS was the nature of the relationship between the administration and the services or service providing organisations. In Kensington and Chelsea for example, this was arms length through the functional and separation of purchasing from providing and the contract. Whilst this helped manage change, it also required devices such as representation on the partnership board to ensure that purchasers and providers were working towards the same objectives. In Hamburg and Rotterdam, contracts are set between the care agency or administration and the service providing institutions (services), but largely in the form of block contracts or agreements, adjusted according to actual providing experience.

The extent to which different purchaser-provider relationships represent effective devices for managing change is debatable. For example in Hamburg, both framework contracts and service agreements are planned as instruments to manage change but do not work particularly well in practice due to disincentives to change established patterns of providing. In London the need to manage care markets and monitor placements adds costs to service management. In Catalonia most services are provided by voluntary social care organisations and parent's organisations, which receive financial help from the regional administration. A priority is to collaborate with various providers, especially with not-for-profit organisations. Providers of services do not depend on the local administration but on the regional administration. Thus, there is a link between regional and local factors and responsibilities. In Lidingö, the municipality organises and arranges services directly. Here, there is direct control on the production of services and arguably, more efficiency in the production of welfare, as complex bureaucratic structures and processes are avoided. However, such 'just-in-time' production would be difficult in situations where there is a greater volume and level of demand, with a vast complexity of individual needs and range of service provisions.

A general learning point however, seems to be that the greater decentralisation of learning disability funds and responsibilities within current organisational systems, especially in large urban contexts, will help de-institutionalise services and generate more innovative and flexible service and funding responses.

A range of innovations in advocacy and user representation emerged across STEPS, in addition to the specific local project initiatives, also providing the potential for learning to be transferred between the different learning disability services in the five partnerships. Personal budgets were being piloted in Hamburg and introduced as mainstream policy instruments in Rotterdam (the Netherlands) and London (UK), with the consequent potential for practice and management information exchange and the identification of the relative strengths and weaknesses of such approaches. However, it was also evident that personal budgets alone are no panacea to breaking the mould of institutionalised and inflexible services. Moreover, checks and balances are required to safeguard the rights of service users and staff and accountability for public funds. In addition, organisational, bureaucratic and price disincentives to the take up personal budgets seemed to be emerge, and clearly also need to be addressed if such devices are to achieve their full potential and extent.

User and carer interests were represented in a variety of formal and informal ways across STEPS, largely depending on cultural determinants. In Barcelona service providing organisations must establish mechanisms to promote the participation of the service users and other interests, in Rotterdam and Hamburg parent interests were represented on the boards of services and in London a range of user, advocacy and other interests on the Partnership Board which plan and commissions services. However, there remains considerable scope for developing stakeholder models of representation in services and further promoting self-advocacy. Where developed, self-advocacy groups for people with learning disabilities were proving to be a powerful influence, and thus represent an overall service development priority.

In complex organisational systems, with a host of competing demands, much might be gained from having a learning disability Tsar or public servant charged with responsibility for progressing services for people with learning disabilities, freed from the many organisational and bureaucratic constraints experienced by service managers. Hamburg has a specialist role of Co-ordinator for Equality of People with Learning Disabilities and Kensington and Chelsea have a single manager. Other management
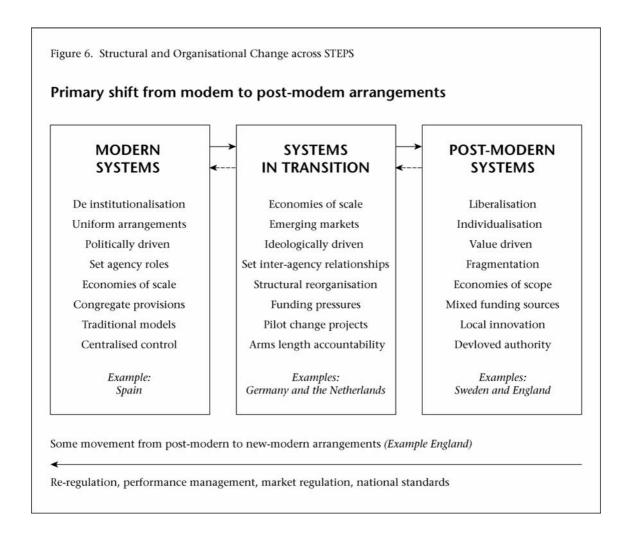
solutions may also be worth exploring. As early as the 1980s the Audit Commission in England was advocating single managers with single budgets for client group services such as learning disability (Audit Commission, 1986) and the Sir Roy Griffiths was recommending community care managers for a client group or locality (Griffiths, 1988). Similar approaches could be tested in the different local organisational contexts of STEPS, where particular needs for change, improvements, or integrated approaches can be identified. The major potential of Ombudsman type arrangements to combat and challenge discrimination and inequality was also identified across STEPS where such models were employed.

A recurring theme to emerge from STEPS was the tension between organisational and professional interests on the one hand and those of service users on the other. There was evidence in all partnerships that de-institutionalisation, in its widest sense, was leading to more individualised and person-centred services. Person-centred planning and individual budgets were beginning to play a major role in shifting power to service users and carers and a clear priority should be given to extending such arrangements. However, to help achieve such change, professionals also need to devolve authority and managers need to hand over more power to service users and self-advocacy groups.

Regardless of national or regional policies in disability or social care or the degree of specialisation or mainstream provision, an imperative from STEPS is the equality and inclusion of people with learning disabilities achieved by managers and practitioners working in valued ways with people with learning disabilities themselves, through respecting diversity and difference within disability itself as well as that based on culture, race, gender, age and sexuality. Inclusive practice is the first step to the inclusion of people with learning disabilities in communities and society more widely.

3.2.   RESUMÉ

The complexity of national and local policy and organisational characteristics across STEPS is part explained by the location of each national system and partner in the process of service development and change. This variability can be modelled as a transition from modern to post-modern arrangements (Taylor-Gooby, 1994; Penna and O'Brien, 1996). Post-modern analysis helps identify the characteristics associated with the primary stages of such transition and illustrates the key similarities and differences to emerge across STEPS (Figure 6). For example, services in Spain were modernising, with the regional state and city-state centrally involved in service funding, planning and development. In the Netherlands and Germany services can be seen to be in transition from modern to post-modern arrangements, with an emphasis on de-institutionalisation and the development of individualisation and new forms of micro-organisation. In Sweden, being largely de-institutionalised, community based and locally accountable, services reflected a post-modern situation, whereas in England, following a post-modern shift to market economies and the fractures and uncertainties these generated (Cambridge and Brown, 1997), a counter trend towards new-modern approaches was detectable, through greater regulation and central direction.

Figure 6. Structural and Organisational Change across STEPS

Primary shift from modem to post-modem arrangements

MODERN SYSTEMS	SYSTEMS IN TRANSITION	POST-MODERN SYSTEMS
De institutionalisation	Economies of scale	Liberalisation
Uniform arrangements	Emerging markets	Individualisation
Politically driven	Ideologically driven	Value driven
Set agency roles	Set inter-agency relationships	Fragmentation
Economies of scale	Structural reorganisation	Economies of scope
Congregate provisions	Funding pressures	Mixed funding sources
Traditional models	Pilot change projects	Local innovation
Centralised control	Arms length accountability	Devloved authority
Example: *Spain*	*Examples:* *Germany and the Netherlands*	*Examples:* *Sweden and England*

Some movement from post-modern to new-modern arrangements *(Example England)*

Re-regulation, performance management, market regulation, national standards

3.3. COMPARATIVE LESSONS

A number of wider lessons for comparative methodology and process are evident from the European STEPS cross-national study.

Comparisons across STEPS were arguably facilitated by a relatively good 'geographical' match of local partnerships, all five being constructed within relatively urban social and political environments. In London, the Royal Borough of Kensington and Chelsea is an inner London local authority within the wider London city region. The service in Rotterdam is in the largest port city of the Netherlands and Europe's biggest port. Similarly Hamburg, the second largest city in Germany, is also a major port. Barcelona is the regional capital city of Catalonia and a major Spanish port city. Lidingö in Sweden is an independent municipality on the outskirts of Stockholm, Sweden's capital city and port and in terms of social and economic geography is part of the wider Stockholm city-region. All five partnerships therefore have primarily urban characteristics, and although this was not a planned feature, the matching this provides helps towards strengthening the comparative basis of the project, minimising some potentially problematic issues of comparison between urban and rural authorities.

With the development of the comparative framework led by the STEPS project co-ordinator in Hamburg and the local co-ordinator for the English partnership, the initial framework understandably had an Anglo-German bias in its construction and constituent elements, reflecting as it did the known and important characteristics of learning disability services in England and Germany. However, as a consequence, questions relating to social care markets or care management were not relevant for some of the partners where such policy instruments or organisational devices were deemed inappropriate or irrelevant. In Sweden for example, there is no voluntary sector and the local municipality organises services and

support directly, making the market and individual payments irrelevant. However, through a process of consultation and the development of the respective individual national frameworks, it was possible to minimise such bias, with the progressive inclusion of specific national and local characteristics and dimensions.

Another potential criticism of the comparative framework is its development in English, as each national framework was also expected to be in English. Although a common language is necessary to facilitate ready and meaningful comparisons, the emphasis on one language English clearly risks bias, reflecting as it did, the characteristics of English services and organisational and policy systems. This consequently risked disadvantaging particular partners where English was not a second language. For example, the Barcelona partnership in Catalonia required Spanish-English translation for the framework, as well as most meetings and events, limiting participation, free-flowing dialogue and the exchange of information and ideas.

Conversely, with English as the working language of STEPS, an English version of the comparative framework and glossary represents a rational interim output and as is evident from the glossary (see section 9), this does not preclude the use of specific national terms or language. Indeed, a productive aspect of such exchange proved to be the use of specific terminology in the home language where this was understood across the partnerships. It was also observed that social care policy and practice terminology, both in generic social policy and learning disability policy and practice was arguably more developed in English (rather than necessarily meaning more advanced) than elsewhere in Europe, largely owning to a series of recent policy and organisational changes in social care and learning disability.

De-institutionalisation and care in the community was rapidly followed by the 1990 community care reforms (Department of Health, 1989) which introduced the separation of purchasing from providing and the market in social care, including care management and concepts of consumer choice. Subsequent reforms introduced regulation, partnership working between health and social care, national care standards and other initiatives. In addition, the recent national learning disability strategy for England (Department of Health, 2001) introduced concepts such as social inclusion into policy (see also STEPS account: Cambridge, 2003, for full details and references). This experience has provided a sourcebook of policy and practice terminology, and the potential for terms to be developed and redefined where appropriate in their respective national contexts.

There were occasions when discussions concerning respective national developments in services appeared to lead to direct or indirect criticism of particular local or national arrangements. For example the differences between the development and form of community-based services in Sweden, Germany and Catalonia were marked. Comparative studies require such differences to be acknowledged. However it is also essential to ensure that such comparisons are made within respective cultural and historical frames and are developed through positive and constructive criticism. It is important to ensure that we do not condemn or devalue a particular arrangement to the extent that the comparative exercise becomes a competition which ranks different arrangements in order of perceived merit or worth. Qualitative interpretation and interpretative understanding should always lead and inform our comparison and judgements or different arrangements.

A big risk of comparative studies, where services are effectively put on display by each partner or national representative, is that only the best services are used as examples of practice and that some of the more institutionalised or inappropriate services are hidden from view. Part of the challenge of comparative studies is therefore to ensure that an honest and open dialogue is maintained. Indeed in England it is largely considered inappropriate for those not involved in organising, providing, using or inspecting services to view them. As in Sweden, the consent of service users in put foremost.

Finally, it should be recognised that comparative work of this nature is part of an ongoing process of development. No single project can hope to achieve comparisons at all levels or across all domains or factors. The STEPS project focus on anti-discrimination and learning disability, necessarily steered and impacted upon its comparative capacity. In addition, each of the STEPS partners represents a natural system, which is not necessarily representative of other systems within its respective national context.

However, by focusing on one local system it is possible to generate specific learning points in a way that is impossible through generalised national comparisons. Such comparisons should consequently be viewed as part of a wider European and international endeavour, initiated through experience in the 1980s with de-institutionalisation and continued into the new millennium with community care. Each such enterprise will also have to face new and complex challenges, such as the ongoing enlargement of the European Union.

Due to the before mentioned reasons, STEPS consequently represents an 'incomplete' or 'unfinished' body of work. However, it also invites new discussion about different service arrangements and the further exchange of information and experience. It offers many potential links and opportunities to continue with or to enlarge such comparative work through the ongoing cross-fertilisation of policy and practice and the demonstration of successful interventions in learning disability and community care.

SECTION 4. GERMAN PARTNERSHIP (HAMBURG)

Anne Ernst

4.1. PRODUCT 1 – LOCAL PARTNERSHIP PROFILE

Q1. Describe the relationship between the local administration (local government and/or public sector organisations) and the national state in terms of centralisation-devolution

In Germany, both the Federal Government and the states have their own prerogatives and their own responsibilities. The overall state is responsible for matters which need to be dealt with in a uniform manner in the interests of the people. Other matters are determined by the constituent states.

The link between the Federal Government and the 16 states is the 'Bundesrat'. It is the channel through which the states can participate in the legislation and administration of the Federal Republic and in EU affairs.

Hamburg is one of the 16 states of the Federal Republic of Germany. As a City-state Hamburg has a twin role, both as a City and as a 'Land' (i.e. a State of the Federal Republic), and its Parliament (Bürgerschaft) likewise has a twin role, as the elected Council of the City of Hamburg and the elected Parliament of the Land of Hamburg.

The Parliament of Hamburg is called the Bürgerschaft, the Government of the State is called the Senate. Here the head of government is the First Mayor. The ministers of Hamburg are known as Senators. To date Hamburg maintains 10 departmental/ administrative bodies each headed by a Senator (e.g. the Ministry of Social Welfare and Family). The Senate represents Hamburg when dealing with any of the other Federal States, the Federal Government as well as any countries abroad.

Partner in STEPS is the Hamburg Ministry of Social Welfare and the Family. It is responsible for social welfare/social assistance and social insurance (not health insurance), care for elderly people, young people, homeless persons and people with disabilities, accommodation for immigrants, support of social important employment (e.g. sheltered workshops).

Q2. List and describe the local service (providing) organisations included in the partnership and the services they provide

According to the Social Assistance Act (§ 10) the services are provided by organisations of the voluntary welfare work. The Ministry for Social Welfare and Family in general does not run its own (funded) services.

The Foundation 'Das Rauhe Haus' runs services for people with disabilities, young people, elderly people, and a social psychiatry, a school and the University of Applied Sciences for Social Work.

All over Hamburg 300 persons with disabilities enlist the services of 'Das Rauhe Haus':

Residential care in community integrated homes/houses with 5 – 8 places/apartments	125 places in 14 houses	Residential service for people with different levels of support, organised in groups. Paid not individually
Assistance for independent living in external groups	Four groups	People who don't want to live alone rent a flat with other people. They receive individual Assistance.
Pedagogical Assistance in the own apartment		Individual support to integrate people in Society
Guest House	24 Places	Short-break and holiday stays for children and young people/groups
Individual Work Assistance		Employment in small groups with individual assistance and assistance planning
Individual Day Services		Day services for people with higher needs or challenging behaviour
Culture centre	3 centres in Hamburg	Cultural activities in the community for people with and without disabilities

The Protestant Foundation Alsterdorf, as the biggest provider organisation in Hamburg, offers a large number of services in the fields of care and employment for people with learning disabilities, health care, children and youth care. It runs an integration school, Kindergarten and a school for social workers. The services for people with learning disabilities are distributed all over Hamburg. To name the most important services:

Residential care at the area of the Foundation (department AlsterDorf)	420 places in 8 houses of different sizes	Residential service for people with different levels of support, organised in groups. Paid not individually
Residential care in community integrated homes/ houses in the City of Hamburg (department HamburgStadt)	Around 800 places in 33 houses of different sizes	Residential service for people with different levels of support, organised in groups. Paid not individually
Residential care in community integrated homes/ houses in the surrounding area of Hamburg (department HamburgUmland)	Around 240 places in 15 houses	Residential service for people with different levels of support, organised in groups. Paid not individually
Pedagogical Assistance in the own apartment		Individual support to integrate people in Society
Day Services	Day centres in all departments of Alsterdorf, small employment projects	Support of abilities and preparation for employment
Sheltered Workshops	More than 10 locations in Hamburg	Employment opportunities varies from art/culture, bakery, agriculture, a Café and a bicycle workshop

Q3. List and describe any other local services providing organisations and the services they provide

In Hamburg, many other organisations from the voluntary welfare work run services for people with learning disabilities, e.g. Arbeiter Samariter Bund, Rotes Kreuz (Red Cross) or Diakonisches Werk (Protestant Welfare Organisation).

Additionally many associations, user organisations, foundations, parent's organisations etc. offer special services, support and information for people with learning disabilities. (A list of addresses in an advisory book includes 40 pages!)

Q4. List and describe the local administrations (local government and/or public sector organisations) included in the partnership

As above, question 1
The ministry design and govern social welfare-, youth- and family policy in Hamburg. The main tasks are advice, granting of benefits and services and monitoring according to the political aims, efficiency and reasonableness.

Participants in STEPS are members of the Department 'Social Welfare and Integration: Rehabilitation, Care for Elderly, Care and Assistance, Integration Assistance'.

Q5. List and describe the other local administrations relevant to providing services used by people with learning disabilities

The most important are:
- Social welfare departments in the districts
- Ministry of Education and Sport
- Ministry of Environment and Health
- Employment office (as part of the federal employment office)
- Senate's co-ordinator for equality of people with learning disabilities (independent, elected by the Hamburg Senate)

Q6. Specify the relationship/links between the local academic institution or department and the local administration in the partnership

The HWP – Hamburg University for Economics and Politics offers an advanced vocational training 'business management' for employees of the Ministry.
Michael Langhanky as well as other researchers from the University of Applied Sciences carries out examinations and research on behalf of the Ministry.

Q7. Specify any other relationships the academic partner has with the local administration or local service (providers)

Because of the close connections in the City State Hamburg there are numerous relationships between the academic partners and the local administration and service providers in the field of education/further education, research, advice, and as well personnel. All members of the STEPS project co-ordination and local STEPS partnership were in contact before the project started.

Q8. Outline and specify the information members of the local partnership hold on the numbers, characteristics and needs of the people with learning disabilities

A comprehensive data base remains unavailable. Thus, important information is missing (e.g. number of people with disabilities and their needs in Hamburg, average of benefits/ services which a people with disabilities receive in Hamburg, indicators concerning success and efficiency of services, etc).
It is consequently necessary to collect and collate the available data from different sources and reports.

Q9. Outline and specify the information members of the local partnership hold on the costs and resources associated with local services/service models/supports for people with learning disabilities

See above.

Q10. List and describe the service user groups or organisations working with the local partnerships and their activities

In the advisory group of people with learning disabilities in STEPS, the Hamburg partnership works together with:

- the user-advisory boards of the Foundation 'Das Rauhe Haus' and the Foundation 'Alsterdorf' and the user-advisory board of the sheltered workshop of the Foundation Alsterdorf. They are set up of users or employees of the corresponding organisation.
- They participate in decisions and activities in their institution (laid down in the residential home act and the law about participation in sheltered workshops).
- a member of 'People First – the Strong Angels' self-advocacy group
- Forum e.V., association for support and training for people with and without disabilities (a member of forum supports the advisory group).

4.2   PRODUCT 2 – DESCRIPTIVE QUESTIONS COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

It should be noted that the following questions are answered primarily from the Hamburg perspective and point of view, as the situations described will vary across the 16 federal/ city states in Germany. For additional background information please refer to the IDRESNET-publications (Schädler, 2003, and Schädler et al, 2004).

Q1. What service planning arrangements or strategies operate at the local (partnership) level and how are service users involved?

Background information: quoted Schädler (2004), p. 17:

'In the first half of the 20th century voluntary welfare work was able to impose a government arrangement, which, in line with the principle of subsidiarity, obliges the state to leave the provision of social services to the voluntary welfare organisations while also obliging the state to bear the relevant cost. In principle, this arrangement still applies.'

It can be stated, that

> *'in Germany now the situation is characterised by powerful third-sector organisations and a state that attempts to release itself from the role of mere funder through legal amendments.'*

According to § 93 Social Assistance Act (BSHG) a contract commission with members from the Ministry of Social welfare and Family, the associations in the voluntary welfare sector and private provider associations concludes a framework contract for services for people with learning disabilities in Hamburg. The contract stipulates the general questions of payment/funding of integration assistance according to the Social Assistance Act, necessity, the content of service agreements with the service providing organisation, and quality management.

The Ministry concludes a service agreement with each service providing organisation covering the content, extent, and quality of services and also costs to realise a prospective payment system. Up to now service users are not involved, neither in negotiating the framework contract nor in the service agreement.

Q2. What individual (person-centred) service planning arrangements operate locally and how are service users involved?

§ 46 Social Assistance Act (BSHG) lays down that the Ministry of Social Welfare and Family – as the responsible body for social assistance – has to draw up a General Service Plan for each user. In Hamburg it should have been organised at the level of the districts. The service user as well as concerned service providing organisations and authorities should be included in the process.

The General Service Plan should include abilities and objectives in the different areas of life, e.g. housing, education, work or leisure, and should define extend of services. It should be updated continuously and should be the basis for the detailed service planning of the service providing organisations.

The General Service Plan is not introduced all over Hamburg. Men and women who apply for services for the first time by the Ministry for Social Welfare and Family receive a General Service Plan.

But only one district uses this instrument continuously – with good experiences. In the other districts benefits mostly are approved on the basis of files and reports.

The Foundations Alsterdorf and Das Rauhe Haus have developed their own in house planning instruments for the detailed service planning. Das Rauhe Haus has implemented 'service conferences' to help plan individual services in co-operation with the user, his/her friends, family members and assistants. These conferences take place once or twice a year.

Alsterdorf has set up 'advisory offices' who carry out 'individual assistance planning conferences' once a year. Additionally they initiate regular conversations in smaller groups and meet the user in order to monitor services.

Q3. How (in what ways) does the local administration (local government) work together with the local service (providing) organisations?

They co-operate in the contract commission and the arbitration committee at the city level and in two working groups. The idea is that they should work together to arrange for the General Service Plans at the district level (Please see questions 1 and 2).

Additionally the administration and service providing organisations work together in other ways, for example
- In the Ministry's approval office: finding the suitable service organisation according to the user's needs and wishes

- in projects, pilot schemes and working groups, with researches to develop the services for people with learning disabilities (e.g. STEPS and 'personal budget' and 'integration of elderly people with learning disabilities' pilot schemes")

Q4. How do the different local administrations (acute health care, social care, education, housing etc.) work together with each other?

According to the Social Code, Book IX, integration and rehabilitation of people with disabilities, all involved administrations and organisations have to co-operate closely. That are besides the ministry for social welfare and family and the social service departments for example the youth welfare and the insurance (pension-, sickness-, long term care and accident-insurance). They co-operate for example in working groups or committees.

Q5. What are the eligibility/legal criteria for access to learning disability services nationally and/or locally?

In general all Social Code Books include criteria and regulations for entitlements to services.

All people with disabilities or at risk of becoming disabled are entitled to rehabilitation benefits (medical and occupational and welfare benefits), regardless of the cause of their (potential) disability. This right is laid down in Book XI Social Code 'Integration and Rehabilitation of Disabled People'. Book IX defines 'disability' according to the definition of the World Health Organisation: People are disabled if physical functions, intellectual abilities or mental health differ from the characteristic condition in an age group probably for more than six month and if therefore participation in society is restricted not only temporary. A disability is generally determined by a doctor in consideration of the individual case.

Book IX Social Code includes the law for people with severe disabilities who are entitled to special employment protection provision and special benefits to compensate for disadvantages (tax concessions, free public transport, and so on). Therefore it is necessary to determine that a person's level of disability is at least 50%. The level of disability is determined by the local administration (Versorgungsamt), expressed in 'ten-steps' between 10 and 100. Basis are 'advice for medical experts', published by the Federal Ministry for Labour and Social Affairs.

Q6. How integrated are services for people with profound and multiple learning disabilities (PMLD) with services for people with learning disabilities more generally?

By law all people with learning disabilities should be supported to participate in society and receive support to compensate disadvantages. In general all services should be accessible for all, independently of kind and degree of disability.

In practice equal access for people with profound and multiple learning disabilities is not realised in the field of living and employment, leisure time, education and further education etc. In housing and employment there is a lack of integration of people with profound and multiple disability in services. For example housing: Pedagogical assistance in the person's own home can in practice only be realised for people with mild disabilities. People with severe disabilities describe high barriers and risks which keep them from entitle personal assistance and force them to stay in residential home. Those living and working in groups with mainly people with profound/multiple disabilities are rarely in contact with people with mild disabilities or with society more widely.

They are not reasonably represented in the user-advisory councils.

There is a discussion about the right of risk and shelter: Some professionals and parents argue that people with profound and multiple disabilities need the shelter and care of residential settings to be protected against poverty, isolation, neglect and abuse. This argumentation is strengthened in the context of savings in the field of social services.

Nevertheless, there are first attempts and projects to foster integration of people with severe disabilities and to reconcile shelter and self-determination (e.g. small working projects in the community, integration of people with severe disabilities in community integrated houses).

Q7. How integrated are services for people with challenging behaviours with services for people with learning disabilities more generally?

As above. More than other groups of people with learning disabilities they remain dependent on special services for people with challenging behaviours. There are first activities to combat discrimination against these people, e.g. workshops to get in contact with and to understand challenging behaviour, working groups to develop assistance strategies and practices to integrate people with challenging behaviour in services for people with learning disabilities more generally.

Q8. What types of advocacy arrangements are there for people with learning disabilities locally and which are the most inclusive?

Advocacy does not have such a strong tradition in Germany as in other countries.

Based on the idea of self-help there are some user advocacy groups e.g. People First, the Strong Angels, Association for Blind People, Autonomous Living. They offer advice, personal empowerment, exchange of information, public relations and lobbying. Some of these organisations are members of international organisations as Independent Living.

On the federal level and in some states (not in Hamburg) advisory councils of people with learning disabilities have been established to advise and monitor the government and the administration and to stand up for their rights and interests.

In the frame of the equality law for people with disabilities the Ministry for Social Welfare and Family plans to establish an advisory council as well. The council should co-operate with the Senate's Co-ordinator for equality of people with learning disabilities. However, it remains doubtful as to the extent to which people with learning disabilities are reasonably represented.

In sheltered workshops and in the service providing organisations there exist statutory user advisory councils. Again however, their practice influence is limited.

More influence than self-advocacy groups have been parent-groups in changing services (e.g. associations Living with Disabilities, Parents for Integration). In the meantime some groups have also developed into service providing organisations and offer services as well as campaigning.

Legal guardians are obliged to strengthen the voice and self-determination of people with learning disabilities, and are required to be involved in every decision-making process.

Q9. What complaints or appeals procedures for service users operate locally and how well do they work?

Diverse legal appeal procedures are laid down in the Social Code Books. People can appeal against each decision of local authorities.

Corresponding the right to bring a suit in case, rights are disregarded is laid down in Book IX Social Code and in the Equality Act. This is not only an individual right but also a right of associations which represent people with learning disabilities.

The local authorities and court often need a long time to decide about the appeals.

In Hamburg the Co-ordinator for equality of people with learning disabilities investigates complaints of people with learning disabilities, organisations and associations. The status of the Co-ordinator as well as the National Co-ordinator for interests of people with disabilities is comparable to the status of an ombudsman in other countries.

There are also complaint processes within the service providing organisations themselves, managed for example, by the 'complaints representatives'.

Q10. What service models for learning disabilities are being promoted nationally and/or developed locally?

The Social Code Book and the Social Assistance Act provide for residential, partly residential and non-residential/individual services. Services providing organisations offer services for all areas of life: housing, leisure, work, education.

In Hamburg, the Ministry for Social Welfare and Family supports the so called '2-milleu-principle': Housing and Work/Education should be separated from each other.

Guidelines (nationally and locally):
- Support of prevention, self-determination, participation.
- Rehabilitation has priority towards pension.
- Priority of non-residential, community integrated services towards residential services.
- Personal budgets, individual payment and 'flat rates' for services and budgeting should be developed.
- Development of family support services.

Q11. What is the national and/or local evidence of a relationship between different service models and costs?

Most evident is the division of the German service system in residential/partly-residential and non-residential, so called 'community integrated services', which are paid individually. Although all services are financed by the Social Assistance, the two systems are strictly closed off from each other referring administration. This is one of the most discriminating factors in Germany.

This is even more difficult in the face of the development of residential care (community integrated group homes) and the knowledge that, however, self-determination can only be realised outside the residential care system.

Residential care is financed institutionally according the prospective payment system: In the frame of the service agreement the ministry agrees on performances, payments and quality for services in advance. This finance model includes high security for the service providing organisations and (compared to individual funding) predictability for the users.

The disadvantages for the users, which among others include less self-determination and missing free choices, complex services and dominance of the service providing organisations need to be stressed under this arrangement. The financial disadvantages of residential care are an expensive system with high overhead costs but also with little or no flexibility.

Community integrated services, e.g. assistance for independent living, are granted per hour of assistance. In practice people get an average 7 to 8 hours per week. According to the idea of rehabilitation, the

intention is to gradually reduce individual hours. For the user as well as for the organisation, community integrated services are much more difficult to apply, maintain and manage. Therefore they tend to be limited to service users with less needs, who are nevertheless in danger by poverty and overtaxing regarding reduction of assistance.

The organisations depend on demand within a demand led system. They fear a lack of planning reliability, difficult personnel management and a gradually decreasing demand for services. Both service users and service providing organisations, suspect this system of community integrated services of being a saving instrument. The authority fears that by promoting community integrated services, demands will increase because people who currently live with their families and have not yet received formal services will enlist support.

By law, the priority of community integrated services is laid down, but in practice this is not realised. In Hamburg more than 90 percent of the funds are trapped in residential care, with funds for community integrated services strictly limited.

Q12. What are the staff training and staff development programmes and priorities within local service (providing) organisations?

Rauhes Haus:
College/Vocational school for care for elderly people: training as a geriatric nurse (3 years).

Protestant University of Applied Sciences for Social Work:
Education of social workers/social pedagogues and deacons (4 years); masters degree 'Community Economics' (2 years); continuing course 'social welfare work in the community' (parallel to employment, 1/2 year).

In co-operation with the Institute of Social Practice: continuing course 'social work' (parallel to employment, 4 years).

Institute for Social Practice: continuing course 'supervision' (parallel to employment, 4 years).

Foundation Alsterdorf:
College/vocational school for educators (Heilerzieher): training (3 years).
College/vocational school for speech therapy: training (3 years).
College/vocational school for nursing: training (3 years).

Both organisations have in addition internal further education for the permanent staff.

The priority is to train the students according to the principles of self-determination, self-responsibility, human rights, participation, regional and community based services.

Q13. What national and/or local requirements exist for specialist or professional qualifications within learning disability or social care?

In Germany there are numerous training courses and professions (nurse for elderly, educator, hospital nurse, assistant for social care, social worker etc.) and many academic courses and degrees in the field of social work (social pedagogues, social workers, deacons, new: care management, public health, social and health management etc.). Generally, a distinction is made between care, therapy/treatment and education/training/advice.

There are many regulations and requirements for qualification, according to and dependent upon different professions and posts.

One (extreme) example: In § 9 and 10 of the 'regulation for sheltered workshops' (passed by the Federal Government in 1979) it is determined: The manager of a sheltered workshop needs a commercial or technical degree and experiences or further training in the field of social work. For pedagogical, social and medical assistance should stand by a social pedagogue or a social worker. Each pedagogue should normally assist a maximum 120 persons, etc.

Some of the consequences of strong regulation include:
- The employees have more special knowledge than competence in co-operation and social skills. It advances thinking and acting in strict categories, preventing permeability, development and co-operation.
- The training courses and academic courses are behind the developments in the practical fields. New requirements and competence are needed.
- Staffing is consequently a very important/significant cost factor in services.

There is a development towards reform, with deregulation and the reduction of requirements (For example, is it necessary that the housekeeping assistant or the assistant for leisure time need training in social work). Further education on the job should be advanced. The quality of services and quality assurance should also be considered in this context.

Q14. What is the extent of the development of the social care market nationally and/or locally?

In Hamburg as in Germany, politics and authorities intend to foster market mechanisms in the field of social work. This process is still at its beginning. Key words are: output-orientation, prospective payment system, introduction of products, controlling, benchmarking, competition to realise savings. The idea to introduce a free market economy has failed so far because of a lack of belief and commitment – trust, solidarity and responsibility.

In the scope of the modernisation of administrations, the idea to introduce market mechanisms is based on the objectives 'service orientation, efficiency, flexibility, more offers, cost effectiveness'.
Additionally private service organisations are beginning to offer services for people with learning disabilities.

The critical view on the introduction of market mechanisms stresses firstly the cumulative loss of political governance (corresponding to the experiences within the 'market' for care for elderly people and youth care in Germany) and secondly an increase of exclusion is feared because of the weak voice and power ('market position') of the users, who are often not prepared to make informed and independent choices. The service providing organisations fear to loose power and their oligopolistic position.

On this background the local authority would see itself responsible for the quality of services which would be paid by public funds. Advocacy and legal security are deemed absolutely necessary in a social care market as well.

Q15. What are the contractual and/or funding relationship between local administrations and service (providing) organisations?

See question 1.
The funding relationship between the local administration and the service organisation in Hamburg is generally required to be governed in the framework contract. The administration concludes a service agreement with every service providing organisation which includes details about character and amount of funding and the term (duration) of the agreement.

Q16. What are the arrangements for care standards and inspection (regulation) exist nationally and locally?

With the Hamburg framework contract quality assurance and inspection are agreed (according to § 93 Social Assistance Act). An enclosure to the contract elaborates the details: quality standards for 'structures, processes and results', internal and external quality assurance and a quality assurance report.

Possible internal (carried out by the service providing organisations themselves) quality assurance instruments are for example quality circle, constitution of a quality commissioner, further education and supervision, development of standards, complaint procedures and the interviewing/questioning of service users themselves.

Possible external quality assurance procedures, conducted by independent agencies, are: quality conferences of the service providing organisations, certification according to ISO 9000, seal of quality (e.g. from the Technical Inspection Agency, TÜV), the European instrument EFQM (European Foundation for Quality Management) and benchmarking.

Independently from the contract, most of the service providing organisations have already implemented in-house quality assurance instruments, for example quality commissioners.

Q17. To what extent is cost information individualised in relation to services received by people with learning disabilities?

This is little developed because costings are restrained by residential and institutionalised modes and individualised funding is only beginning to be developed and reviewed.

Individual cost information is available for individual assistance, community integrated services, for example for pedagogic assistance in the own apartment, living assistance.

There is little of no information generally available about individual costs within residential services.

Q18. What are the arrangements for direct payments (personal budgets) to people with learning disabilities themselves?

Statutory the states should carry out pilot schemes about direct payments. Hamburg has started a two years pilot scheme 'Personal Budget' and 'Estimation of flat rates' in January 2003. The scheme is available to/targeted on people with disabilities who already enlist community integrated services. A maximum 100 users should get their budget directly. In the context of savings and difficult regulations to entitle individual services the pilot scheme is not very successfully.
At least, in the actual Hamburg context the users have no advantage from getting a personal budget.

Q19. What are profiles/activities of the voluntary sector (not for profit) organisations nationally and locally in service providing?

The most important service providing organisations belong to the voluntary welfare sector (Foundation Alsterdorf, Foundation 'Das Rauhe Haus').

Other non for profit organisations offer the same spectrum of services: residential care, community integrated services, sheltered workshops, employment assistance, day care, leisure activities, training and more.

Private organisations offer mainly community integrated services.

Additionally there are many self-aid groups and associations (for blind people, deaf persons, physically disabled, autism and so on) offering advice, information, public relations and leisure time activities.

Advocacy groups – People first – the Strong Angels, Autonomous Living etc. strengthen and support self-determination and participation for people with learning disabilities. Public relations and awareness training are part of their services.

Family organisations see question 20.

Q20. What are the profiles and activities of families in caring and/or campaigning for people with learning disabilities?

Most (about 90%) of children and many adults live with their families who support them in all spheres of their lives (in Hamburg – 1.74 million inhabitants – there live about 138,000 woman and men with disabilities – data from end of 2001). In 2003 about 8,000 people receive benefits for social and vocational integration.

A strong parent's movement has fought for the integration of people with learning disabilities in kindergarten, school, employment and leisure time. The most important parents association in Hamburg are 'Parents for Integration' and 'Living with Disabilities' (founded in 1956). Both associations have developed as service providing organisations and act as such. Both are members in the Hamburg working group for people with learning disabilities.

Some small groups have founded living or work projects for their children, for example the hotel 'Stadthaus-Hotel' in the city of Hamburg which is operated by people with and without disabilities.

In the sheltered workshops, advisory councils of parents and legal guardians are established to support and advice the management (referring to self-determination this committee might be deemed antiquated).

At present there is not a strong parent's movement, but young parents naturally claim for their children's rights and self-determination.

Q21. What are the legal and funding relationships between national government and local administrations and/or service organisations in learning disability?

See questions 1 and 22 in this part and question 1 in product 2.

The legislative competence in the fields of health, care and social welfare predominantly is in the hands of the Federal Government.
In other fields, e.g. equality law, the states are responsible themselves. The states themselves are responsible internal matters, e.g. school, police or community-legislation.

In connection with reform of the German federal system and European legislation the legislative competence of the federal government and the states should be reformed.

Due to the history funding relationships are complex in the German Social Welfare system. They are laid down in different Social Code Books which include different service and finance systems.

Most of the life risks are at first covered by insurance which are financed half by the employers and half by the employees:

- Statutory health insurance (benefits medical rehabilitation and participation in social life) and Statutory long term care insurance – responsible: local and national operating health insurance funds
- Pension insurance (medical and occupational rehabilitation and participation) – responsible: Federal insurance institutions for white collar employees; insurance institutions for workers and others
- Statutory accident insurance (medical and occupational rehabilitation and participation) – responsible: accident prevention and insurance association (federal and from the states)
- Unemployment insurance (participation in employment, rehabilitation) – responsible: federal employment office, employment offices in the states

Due to the fact that most people with learning disabilities are not entitled to insurance benefits, most benefits for people with learning disabilities are paid by the tax-financed Social Assistance. People with disabilities or at risk of becoming disabled receive 'Integration Assistance' for residential or non-residential services. Responsible are the social assistance departments in the districts and the cities (City-state Hamburg: ministry for social welfare and family).

To grant benefits easily and quickly the 'rehabilitation agencies' are obliged statutory to establish joint service office for advice and support. In Hamburg, service offices are established, but in practice still not integrated or well established in the service system.

Q22. How does national (central) government policy and/or legal frameworks impact upon local administrations (government) and service (providing) organisations?:

Preface: In accordance with the German federal structure many fields are defined by national law (as legal frameworks). The acts open up scope to the states to realise the law in own implementing regulations.

Federal law determines social welfare. Legal foundations are

Federal Social Assistance Act (BSHG)

Federal Social code
- Book III: Unemployment insurance
- Book V: Health insurance
- Book VI: Pension insurance
- Book VII: Accident insurance
- The most important one is Book IX (since July 2001): Integration and Rehabilitation of people with disabilities (with the Act for people with severe disabilities included) – contains all regulation for benefit of the people with disabilities
- Book XI: Long Term Care Insurance

The social code book IX aims at comprehensive and quick benefits for people with learning disability. It should guarantee comprehensive advice and co-ordination of services. Many aspects are still not realised and in discussion.

All social code books have laid down individual claims, structures and standards for services and service providing organisations.

Equality :

The right to equality is laid down in the Basic law, Article 3 [Equality before the law], paragraph 3: …. 'No person shall be treated unfavourably because of disability.'

Schädler (2003, p. 12) emphasise as well the Law of Guardianship from 1992 which 'attempts to combine the constitutional provisions 'for the right to free personal development, also with the 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.'

As a legal framework the 'Federal Equality Act for People with Disabilities' came into effect in May 2002. The states have to pass own equality laws. Six states have already done so. The Hamburg Senate is planning to pass the Hamburg equality law after the election in February 2004.

Anti-Discrimination
According to the European Community's legislative framework the member states have to transpose the European Anti-discrimination directives into national law by 2003. In Germany, an Anti-Discrimination Act has not yet been passed.

Besides the legal framework the federal ministry for health and social welfare carries out special activities or campaigns for example to promote employment for people with severe disabilities or gender mainstreaming in the field of services for people with learning disabilities.

SECTION 5. ENGLISH PARTNERSHIP (LONDON-CANTERBURY)

Paul Cambridge, Hector Medora and Zenobia Nadirshaw

5.1.   PRODUCT 1 – LOCAL PARTNERSHIP PROFILE

Q1. Describe the relationship between the local administration (local government and/or public sector organisations) and the national state in terms of centralisation-devolution

The relationship between central and local government is complex and the levels of centralisation and de-centralisation vary from government to government. More recently there has been a push towards greater monitoring from the centre for poor-achieving organisations. Organisations such as RBKC which are high achieving are given greater freedoms in relation to spending and auditing.

Q2. List and describe the local service (providing) organisations included in the partnership and the services they provide

In/out authority	Type	No.	Services provided
In house	Residential	18 units	Residential services for people requiring different levels of support.
In house	Short-breaks and respite		Providing respite and short breaks for people with learning disabilities (complex → low support).
In house	Day Services	35 places	Day services for people requiring medium to high levels of support.
In house	Community Services	12 places	Community based services for people using ordinary facilities.
In house	Employment Services		Recruitment agency providing support to people with learning disabilities to find ordinary employment.
Independent	Residential providers (5)	30 units	Residential services for people requiring different levels of support.
Independent	Residential and day time		Funded through Supporting People and other sources.
Voluntary	Advocacy (self and citizen) x 3		Organisations providing advocacy services to people with learning disabilities
Voluntary	Social and support x 2		Providing a range of services from social clubs to special interest groups and information to disabled people and their carers
Voluntary	Range		A number of other organisations eg. older people, disabled, mental health, not specifically for people with learning disabilities will offer support and information.

Q3. List and describe any other local services providing organisations and the services they provide

As above

Q4. List and describe the local administrations (local government and/or public sector organisations) included in the partnership

In addition to the Tizard Centre, which is a specialist department of the University of Kent, the partnership comprises the Royal Borough of Kensington and Chelsea Social Services Department (RBKC) and Kensington and Chelsea Primary Care Trust (KC PCT). The Learning Disability Partnership Board symbolises the relationship between the public service agencies locally within the partnership, notably RBKC and KC PCT, but also has membership from the following constituencies or interests:

Users x 3, Carers x 3, Health x 4, Social Services x 4, Education x 1, Housing x 1, Employment x 1, Voluntary organisations x 2, Independent organisations x 1.

Q5. List and describe the other local administrations relevant to providing services used by people with learning disabilities

Most mainstream services e.g. education, libraries, housing, leisure, health, information services, specialist transport are largely provided by or organised by the RBKC. Others such as general practitioners and acute health are organised and provided within the NHS by provider trusts. Welfare access and benefits are provided via local authorities (e.g. housing benefit) or directly by local offices of the Department of Social Security or Employment (job centres). Public transport is co-ordinated by the Greater London Authority.

Q6. Specify the relationship/links between the local academic institution or department and the local administration in the partnership

The main existing relationships between the three partners were informal, such as collaboration for research (e.g. intimate and personal care) and publication (Tizard Learning Disability Review and race and culture) and with service development links in psychology. The Tizard Centre does operate a university affiliated programme with local learning disability services provided in Kent but these are unconnected.

Q7. Specify any other relationships the academic partner has with the local administration or local service (providers)

As above

Q8. Outline and specify the information members of the local partnership hold on the numbers, characteristics and needs of the people with learning disabilities

RBKC in partnership with health services and the Imperial Medical School designed a register for people with learning disabilities. This is a very comprehensive data-base giving extensive details about the person – it is then possible to aggregate information for long term planning. The Royal Borough is also piloting the Person-centred Planning process with 26 users. The longer term intention is to merge all this information in to the Department's database for all service users so that up dating and amending will be much more systematic and routine rather than stand alone.

Q9. Outline and specify the information members of the local partnership hold on the costs and resources associated with local services/service models/supports for people with learning disabilities

The Joint Investment Plan and the joint finance data available for the PCT and Local Authority is also available to the Partnership Board and includes financial and development planning information, including costs and resources.

Q10. List and describe the service user groups or organisations working with the local partnerships and their activities

- Equal People (the local Mencap group)
- Its My Life Group (a user group elected by people with learning disabilities to represent their needs)
- People First (self advocacy organisation with a membership of 35 disabled people)
- Full of Life (a parents and children organisation)
- Quality Network Group (users and providers working together to improve the standards of services available).

5.2. PRODUCT 2 – DESCRIPTIVE QUESTIONS COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

Q1. What service planning arrangements or strategies operate at the local (partnership) level and how are service users involved?

Learning Disability Partnership Board (6 monthly), Forum for People with Learning Disabilities (3 monthly), Quality Network run with British Institute of Learning Disabilities (3 monthly). Users are represented on all of the above and lead the User Forum and help run the Quality Network which reviews services.

Q2. What individual (person-centred) service planning arrangements operate locally and how are service users involved?

Individual service reviews (at least 3 monthly) with users, care managers, providers and/or carers, Person-centred Planning meetings, led by the service user and detailing their aspirations and wishes. PCP is currently being implemented as part of a national pilot but will become part of the wider individual review process in due course.

Q3. How (in what ways) does the local administration (local government) work together with the local service (providing) organisations?

Partnership Boards (for each service user group) define the working relationships between RBKC Social Services Department and K and C Primary Care Trust. Representation includes service providers, carers and users, employers and other agencies such as education and housing. Responsibilities are specified through contracts between the commissioner (joint commissioning by SSD and PCT through the PB) and different providers. These comprise a core contract and individual specifications concerning the service user. Contracts are monitored and reviewed at varying levels through the Quality Network as well as individually through individual service reviews and as part of the business review.

Q4. How do the different local administrations (acute health care, social care, education, housing etc.) work together with each other?

As above through the PBs but also through 'integrated services', with a single manager with overall responsibility for services for people with learning disabilities in Kensington and Chelsea. There is integrated provision – a continuum of care within a wider service strategy for people with learning disabilities – under the remit of the PBs and LD user forum.

Q5. What are the eligibility/legal criteria for access to learning disability services nationally and/or locally?

No statutory eligibility criteria nationally (see Glossary – Product 3). There is a broad requirement in Valuing People, where disability has been identified in early years. Service receipt is subject to a local authority (social services) needs assessment and in RBKC a psychological assessment is undertaken for people with learning disabilities, utilising a range of criteria.

Q6. How integrated are services for people with profound and multiple learning disabilities (PMLD) with services for people with learning disabilities more generally?

Some specialist services are available, to provide higher levels of support for people with learning disabilities and some needs are met by specialist placements outside K and C (about 25%), for example some people with autism and challenging behaviours.

Q7. How integrated are services for people with challenging behaviours with services for people with learning disabilities more generally?

As above. The Community Team headed by a clinical psychologist (and supported by a care manager, a speech and language therapist, a community nurse and an assistant psychologist) provides support to staff, carers and users with challenging behaviours and there are special funds to provide support to people with CB in community based services.

Q8. What types of advocacy arrangements are there for people with learning disabilities locally and which are the most inclusive?

Learning disability User Forum, People First (national self-advocacy group has a local base group of 30 members), Equal People (local group of national MENCAP), Quality Network with BILD, local advocacy alliance (where care managers and users can buy an advocate from a bank of citizen advocates) and advocacy from various other independent organisations.

Q9. What complaints or appeals procedures for service users operate locally and how well do they work?

Customer complaints process within social services, managed by the director. All learning disability related complaints seen by the Head of Disability Services. Written responses provided and independent review offered if necessary. Stage 1 – care manager or team manager, Stage 2 – Head of Disability Services and director, Stage 3 – elected member of the council, Stage 4 independent review and/or local government ombudsman (see glossary). Complains relating to clinical/health issues are addressed through procedures within the PCT via the Head of Disability Services.

Q10. What service models for learning disabilities are being promoted nationally and/or developed locally?

Independent living, small group homes and supported living. Mainstream facilities for leisure, education and employment. Some people requiring greater levels of support still need buildings based services or resources which are not institutionalised. Ordinary employment is through Kensington Recruitment, work projects, job clubs and re-employment agencies.

Q11. What is the national and/or local evidence of a relationship between different service models and costs?

Locally, independent living is not an inexpensive option and it incurs start up costs. But over time community care costs are lowering. For example, for one female service user costs reduced from £1,200 a week to £800 a week and now up to 7 hours a week at £10 per hour from home care. Cost effectiveness is less easy to define as it depends on productivity and outcomes. The most expensive services for people with learning disabilities in RBKC are those for people with challenging behaviours and profound and multiple learning disabilities and the range of service costs for CB are from £800 to £1,800 a week (2002/3 prices). In the future RBKC plan to look at Supporting People packages in relation to those with CB and PMLD, as it is currently particularly viable for people with low support needs.

Nationally, de-institutionalisation has incurred double funding as institutions close and community services develop. The 12 years on research (Cambridge et al, 2002) indicated that costs of community care initially rise, but that this is accompanied with an increase in productivity (outcomes). Costs subsequently fall slowly. Independent and supported living are less expensive generally, using comparable and comprehensive costings, than nursing and residential homes and group homes, but the latter types do support less able people who need more direct care and support.

Costs associated with accommodation comprised between 70-90% of total care costs. There was no evidence of an association between costs and outcomes. The total mean accommodation costs (1998/99 prices £) were 756 for residential/nursing homes, 730 for staffed group homes, 577 for hostels, and 433 for minimum support (although ranges varied considerably). The total mean weekly service package costs also varied – 823 staffed group homes, 797 residential/nursing, 610 hostels, 438 minimum support.

Mean weekly accommodation costs also varied between sectors – 914 in NHS, 682 in local authority social services, 670 in voluntary organisations, 514 in private organisations and 309 in minimum support.

Q12. What are the staff training and staff development programmes and priorities within local service (providing) organisations?

RBKC was involved in a project with Rob Greig about developing a training framework prior to Valuing People. Service providers have signed up to it and it has been accredited by an education provider. It has developed into a training consortium with LBs Hammersmith and Fulham and Westminster – an inter borough initiative led by RBKC. Current training themes include autism, challenging behaviour,

managing personal relationships, working across boundaries. Five places are made available for each authority (borough) in National Vocational Qualifications (NVQs) in Social Care (level 2) each year. The commissioners plan and provide this as part of their contract with providers.

Q13. What national and/or local requirements exist for specialist or professional qualifications within learning disability or social care?

Valuing People sets a 'Workforce Development' target for 2005 for 50% of the social care workforce being qualified to NVQ level 2. Managers requirements (also monitored through Care Standards) in domiciliary and residential care services is the same for NVQ level 4. Each professional also has accreditation via their respective professional body (for example nursing, psychology, speech and language therapy and social work). Care managers have codes of conduct and social work or nursing qualifications.

Q14. What is the extent of the development of the social care market nationally and/or locally?

There are a number of local providers for up to people with medium support needs and two independent providers for people with complex needs or challenging behaviours. However, demand for services for people with autism or Asperger's is not met locally, so it is an imperfect market and some providers are slow or reluctant to provide for people with complex needs or dual diagnosis.

In total there are 6 provider organisations in the borough and over 100 placements for different individuals in around 70 different locations. 96 placements are bought from providers for residential placements and other support services.

Nationally, the care market varies considerably from authority to authority and partly depends on whether commissioners purchase jointly and have an agreed service strategy to inform purchasing and market mix. Research indicates distorted and imperfect markets and at best 'quasi-markets'. Some local authorities are pro-active market managers while others are more into free market ideology.

Q15. What are the contractual and/or funding relationship between local administrations and service (providing) organisations?

Core contracts with providers are set and in addition individual needs are specified contractually based on users assessed needs and PCP. Contract compliance and individual needs are reviewed every six months.

Q16. What are the arrangements for care standards and inspection (regulation) exist nationally and locally?

Nationally monitoring by inspectors of the National Care Standards Commission (annually) and various audits by Social Services Inspectorate, Department of Health and Audit Commissions on local authority services. If a local authority is seen to perform very well (as is the case with RBKC) then it receives a three star rating. Three star authorities do not get audited as regularly as other authorities as their performance is deemed to be excellent in the first place.

Locally, regular monitoring by Residential Placements Officers of people in residential and nursing homes (at least twice yearly). In the local authority senior managers also visit establishments regularly (for example Hector Medora does this monthly) to look at various records, etc. and meet with staff and residents.

The opportunity to meet with staff and service users also arises at various meetings and consultations throughout the course of the year.

Q17. To what extent is cost information individualised in relation to services received by people with learning disabilities?

The RBKC has IT systems, which provide records of the costs of individual packages of care. There are also finance systems that allow for the aggregation of costs. It is not so clear in health provision (formally transferred in April 2003) and work is now commencing to include the cost of health inputs into care packages to provide an integrated system.

Q18. What are the arrangements for direct payments (personal budgets) to people with learning disabilities themselves?

These have been made available and publicised. Expansion of the Direct Payments Schemes and a variation in the national guidelines should encourage a greater take up of Direct Payments. In RBKC, we have not been successful in getting people onto the scheme, largely because people do not want to take on the role of employer or purchaser. The Borough (RBKC) also has a number of other options that may offer users choices they prefer.

Q19. What are profiles/activities of the voluntary sector (not for profit) organisations nationally and locally in service providing?

There are a number of national organisations delivering services for people with learning disabilities e.g. MENCAP, the National Autistic Society, Values Into Action, People First. The Borough works with all these and other local organisations – there are for example local MENCAP and People First groups. Additionally, locally there is an advocacy organisation. There are a number of other organisations supporting people with disabilities. Furthermore there are a very large number of independent organisations that sell day and residential services purchased by the Borough for its residents.

Q20. What are the profiles and activities of families in caring and/or campaigning for people with learning disabilities?

The Borough (RBKC) has a parents' group for younger people with learning disabilities (Full of Life) and there is also a parents and carers forum with a very active membership. Three parents/carers are on the Partnership Board.

Every carer/parent has the right to a full assessment of their needs as well as the person they help to support and this is offered as a part of the care assessment. The Carers Grant, made available through central government, is further used to support individuals and organisations providing services and support for carers themselves.

Q21. What are the legal and funding relationships between national government and local administrations and/or service organisations in learning disability?

The government funds local authorities to deliver services using data from past performance and population data to determine the levels of need locally. There are also specific grants available which are ring-fenced (protected for used) for services for certain service groups (although ring-fencing is not a mechanism which applies to 3 star local authorities like RBKC).

The borough has contracts with individual organisations, including spot or one off purchases for particular services or individuals and longer three year funding contracts (block purchasing) for services purchased from voluntary provider organisations. Some independent (private/commercial) provider organisations are also used as well as some in-house provision by the local authority itself.

Q22. How does national (central) government policy and/or legal frameworks impact upon local administrations (government) and service (providing) organisations in:
   1. *social care*
   2. *health care*
   3. *learning disability*
   4. *anti-discrimination*

A range of statutes, guidance and other legal directives and rulings govern local government. The PCT is also accountable to the Department of Health for its activities and service delivery.

Specifically for learning disabilities, in England, *Valuing People* provides the latest policy framework for developing services. Each local authority is monitored on the services it provides and funds are made available annually through the Learning Disability Development Fund to support new initiatives. This is in addition to other legislation and funding already made available through the annual funding of the NHS and health services and local authorities.

In addition, there exist various pieces of legislation to support public bodies in promoting anti-discrimination, including the Race Relations legislation, Sex Discrimination Act, Disability Discrimination Act, and so on. New legislation to protect homosexuals from discrimination is also planned for later this year.

SECTION 6. DUTCH PARTNERSHIP (ROTTERDAM)

Els van Kooten and Bart Branderhorst

6.1.   PRODUCT 1 – LOCAL PARTNERSHIP PROFILE

Q1.Describe the relationship between the local administration (local government and/or public sector organisations) and the national state in terms of centralisation-devolution

The system is in its execution very de-centralised. The national law (AWBZ) is executed through local health care administration offices (Zorgkantoren/ZK) that have some 'room for interpretation' and a level of political freedom. They can do more than the have to by providing permissive services, but cannot do less then prescribed.

There is no relationship between the ZK and local government and there is no 'national entity' that can over-rule decisions by the ZK, so long as they stay between the boundaries and financial borders of the AWBZ law.
Only with complaints national organisations can be activated, for example, the National Parent Organisation and the Health Inspectorate.

Q2. List and describe the local service (providing) organisations included in the partnership and the services they provide.

INHOLLAND nor OMIJ Rijnmond are the providers. In the partnership PameijerKeerkring is the only provider of services and support.
As such it is one of the three organisations forming the Maaskringgroep.
The other two are: Maasstad and RIBW Rijnmond foundation.
The organisations offer a wide range of services and support to people with disabilities in all age groups in the area around Rotterdam and the city itself – living arrangements, work (day activities) and education, and leisure time activities – both for people with learning disabilities and people with chronic psychiatric behaviour.

Maasstad offers treatment, education and support to youngsters with (mild) learning disabilities and behavioural disorders. The support stretches from individuals to the wider social environment. The Maaskringgroup supports people in their own social environment as much as possible. To do this, the organisation works in close co-operation with all possible social partners. Support and care is organised on the basis of needs (assessment) and on the phases a person experiences.

Support is individualised. Every life phase – childhood, youth, adulthood, senior status, old age – has its own area of expertise, attention and orientation. The personal circumstances (background, demands and expectations) play a dominating part in the (organisation) of services and support.

Q3. List and describe any other local services providing organisations and the services they provide

There are some 7 other organisations providing services in Rotterdam. Some of these are more specialised in what they offer. Some concentrate on housing and living arrangements (e.g. the Pope John XX111 charity or the Charity HOMES PC (Protestant Christian).

Others specialise in work (like the Rotterdam Sheltered Workplace)
The local Social pedagogical service (SPD), named R'go in Rotterdam is an independent organisation where disabled people or their parents may go for information. Social workers also point the way to possible services and organisations providing these.

Q4. List and describe the local administrations (local government and/or public sector organisations) included in the partnership

This is not a valid question for the Dutch situation. Local government may stimulate social firms (like OMIJ Rijnmond) and some social firms work together with service providers. However, there is no direct contact between the local administration and the partnership.

Q5. What are the eligibility/legal criteria for access to learning disability services nationally and/or locally?

Parents of disabled children as well as disabled adults usually go to R'go, the local organisation for social work (SPD) and from there find their way to day centres and/or paid employment (such as supported employment schemes or sheltered workplaces) or support in housing, social network development or whatever.
There is no local administration involved: it is the civil society executed by independent (Voluntary) professional organisations.

Q6. Specify the relationship/links between the local academic institution or department and the local administration in the partnership

There is no such relationship. Schools are independent bodies as well as service providers.

Q7. Specify any other relationships the academic partner has with the local administration or local service (providers)

The educational system brings students to the service providing organisations for learning by doing practice, a 'stage-period'.
The students learn to put theory into practice during a certain period and are supervised by someone from university and by a worker in the institute. (N.B. Institute is used here as a term for an organised activity, not as another word for big building or a certain conceptual paradigm for services). Workers in services and support organisations relatively often teach at the university as well. However this is more incidental than it is structural or planned.

Q8. Outline and specify the information members of the local partnership hold on the numbers, characteristics and needs of the people with learning disabilities

The Partnership has no information on numbers and such at all.
Omij Rijnmond nor INHOLLAND have an idea of what demographic developments and/or the characteristics are likely to change.
Data are, however, easy to access. National Organisations (NIZW for instance, the National Institute for Care and Welfare) as well as governmental bodies produce figures on numbers and costs etc. The care providers and the Health Insurance Offices (ZK) have access to these figures as basis for their strategic planning.

Q9. Outline and specify the information members of the local partnership hold on the costs and resources associated with local services/service models/supports for people with learning disabilities

There are no local resources. The partnership can get any information it wants at any time but there is no imperative to do so. The partners have their own budgets which are not related. Service providers receive money from the AWBZ (see Product 3 – Glossary) through the Insurance Offices (ZK).

Q10. List and describe the service user groups or organisations working with the local partnerships and their activities

Service users groups are as follows: Onderling Sterk (for people with learning disabilities) which is supported by R'go (Social Work) and volunteers.

Nation wide 'Ons Belang' is active. They know local groups (branches) and are close to the National Parent Federation (with local branches working together).

Patient's platforms are organised on local levels but they are more for physical care (and cure) issues.

Every service providers has to have its own Client Board and these boards are the most active and successful ones. They have influence on strategic decisions and day to day activities. They also have a strong legal basis. Interest groups such as Onderling Sterk and Ons Belang lack this. There is a strong bilateral contact between the ZK and the service provider.

6.2. PRODUCT 2 – DESCRIPTIVE QUESTIONS COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

Q1. What service planning arrangements or strategies operate at the local (partnership) level and how are service users involved?

There is regular contact between care providers and the ZK (Care Office). This Care Office (ZK) has an advisory body of care users, parents and other family members participate in this body. Service users have the capacity to go to another service provider if they are not content with the offered support in a certain place.

Q2. What individual (person-centred) service planning arrangements operate locally and how are service users involved?

Every service user has to have a personal plan which is updated as much as is needed and at least once a year. Personal Future Planning and PATH planning is used but always facultative (not standard issued from the care provider).

Q3. How (in what ways) does the local administration (local government) work together with the local service (providing) organisations?

See product 2 below. This is not relevant in the Dutch system: in most cases there is no direct contact. Sometimes this happens in the Netherlands through a local Social Firm.

Q4. How do the different local administrations (acute health care, social care, education, housing etc.) work together with each other?

See product 2 below. Tends to be on a strictly voluntary basis – if there is no win-win then there tends to be no contact. There is required to be some level of reciprocity for joint work to happen and be productive and there are no specific incentives for this under the Dutch system (see also 'joint team' under Glossary – product 3)

Q5. What are the eligibility/legal criteria for access to learning disability services nationally and/or locally?

Set within the AWBZ framework by the LCIG (See product 1 under LCIG)

Q6. How integrated are services for people with profound and multiple learning disabilities (PMLD) with services for people with learning disabilities more generally?

In principle there is complete integration, but since many day centres are not accessible, this is not so in practice. The number of people with PMLD has grown faster than was foreseen.

There is a potential danger that the buildings that become vacant when people with milder learning disabilities prefer community care or care in the community, that those more severely disabled take their place, with people slotted into available resources – as opposed to a shift towards integrated creating community services for all.

Q7. How integrated are services for people with challenging behaviours with services for people with learning disabilities more generally?

All 7 modules of the AWBZ know the possibility of extra support, up to 24 hours a day, seven days a week and on a one to one basis. The LCIG, an independent body, appoints and administers these (and other) special arrangements. The situation is comparable with the answer to question 6 above. So far, no financial cutbacks have effected these (costly) arrangements (July 2003) but we foresee problems in the future and dire straits if such questions are not resolved.

Q8. What types of advocacy arrangements are there for people with learning disabilities locally and which are the most inclusive?

Since in principle every arrangement is individualised, then the most inclusive arrangements are those where the disability plays no role at all. That being the situation, if a person with an intellectual disability joins a fishing club, long distance walking organisation or a church choir, then there is no issue – the coming together of people on the basis of their intellectual ability or intelligence is not favoured.

In Circles of Friends and other forms of social networks/social network development, the proportion of participants with learning disabilities is some 90%, but that 'just happens' to be the case – it is not the starting point and is not due to set selection criteria.

There is 'Onderling Sterk', a self advocacy organisation similar to People First, and they are both locally organised as well as having a national board. The social aspect (meeting other people) is here, as everywhere else, very important. Their political influence is also bigger then the number of their member-ship might suggest or justify. The 'easy-to-hug-component' also plays a significant role.

Q9. What complaints or appeals procedures for service users operate locally and how well do they work?

See Ombudsman in Glossary and answer to question 1. If service users do not like it, then there is the potential or the capacity to go elsewhere (the power of the buyer in the (care) market). So the arrangement is seen as ostensibly user or consumer driven in principle.

Q10. What service models for learning disabilities are being promoted nationally and/or developed locally?

As in the English context (see section 4 above), replacing Kensington Recruitment by Social Firms and Sheltered Employment schemes and individual arrangements as described in individual care plans.

Q11. What is the national and/or local evidence of a relationship between different service models and costs?

There are two different systems. First there is the long established and long existing system of services 'in kind'. Under this system or arrangements, the care provider receives subsidies to exploit day centres and other facilities. The individual service/care user receives care and support and has no need to know what costs are accrued. The other system is relatively new (with the first experiments beginning in 1995) and represents variations on the *personal budget* (or direct payment) systems. This new form of financing includes approximately 20% of people with learning disabilities. Since the AWBZ is changing into a care/support modules system, the growth of the number of personal budgets has slowed down. Nevertheless, the total numbers of service users with personal budgets is still increasing.

The government plan is that both systems (in kind, through service providers and personal budgets) are provided for through the same levels of expenditure. Although an effective costs analysis has not been made so far, expectations are that the 'personal budget' system should be no more expensive than financing organisations, but that it should also be more effective and better meet the needs of individuals. Consequently it represents a user empowerment measure more than a financial cut back (according to the administration).

Qs12/13. What are the staff training and staff development programmes and priorities within local service (providing) organisations? What national and/or local requirements exist for specialist or professional qualifications within learning disability or social care?

In the Netherlands the level of staff training/qualification is high in comparison to many other countries. For example, over 50% of the employees have a Bachelors degree in the social sciences.

Current staff development priorities are in network development skills, advocacy and community care more widely (see Glossary – 'mixed economy' and 'care in the community').

Q14. What is the extent of the development of the social care market nationally and/or locally?

Since W.O.2 the parent initiatives have became rapidly more professional. All care providers are now professional organisations. Even where parents are joining together to set up new group homes or their own day services, they seek cooperation with a care provider in the area.

In the Rotterdam area six service providers are active, not counting the several small parent initiatives mentioned above. Of these six PameijerKeerkring is the biggest when it comes to day support services and in housing, the charity holds about 50% of the market. Some of these six organisations also work nation wide. Two of them, PameijerKeerkring being one of these, work locally. All service providing organisations are non-government organisations (NGOs).

In several projects these organisations work together and with other (social) firms outside the disability domain. It tends to be the care providers that are pro-active or not, the role of the local government being negligible. Together, these six service providers offer the complete range of services, from 24 hour care to 2 hours support and from family support services to care for the disabled elderly.

Being a small country and having the same legislation for the country as a whole the differences between service availability and access are much smaller in the Netherlands than would be found between regions or different local government administrations in most other places in Europe. Moreover, there is a Dutch tradition of equality and equity in service provision and availability.

Q15. What are the contractual and/or funding relationship between local administrations and service (providing) organisations?

The care providers set targets (production days) once a year in advance with the Care Office (Zorgkantoor). These numbers are checked later, during the year and after. In cases of under production the care provider receives a reduced income from that estimated. When service/care users, with or without personal budgets, decide to go somewhere else, the care provider potentially faces serious financial problems – directly (in the case of personal budgets) or later on in time, when the Insurance does its monitoring and review checks.

Q16. What are the arrangements for care standards and inspection (regulation) exist nationally and locally?

See question 15. There are also the Client Boards in which parents and/or relatives or proxies hold seats.

Central government through the Health Inspection function reacts on signals from either one of these boards or from other care providers. Yet this is an uncommon event since the Insurance (Zorgkantoor/Care Office) is in close contact with the care providers – they have the opportunity to meet staff as well as service users throughout the course of the year.

Q17. To what extent is cost information individualised in relation to services received by people with learning disabilities?

Since 2003 all new applications for support are considered on a strictly individual basis. The service packages to which a service user might be entitled, are composed out of seven main modules (see Glossary, product 3 – AWBZ/insurance) or from the persons receiving support, since an earlier date within the AWBZ legislation some 20% have a personal budget. In the other cases cost information is not individualised.

Q18. What are the arrangements for direct payments (personal budgets) to people with learning disabilities themselves?

Anyone can apply for a personal budget. However, a significant proportion of service users and their carers are reluctant to do so because of the paperwork involved.

Q19. What are profiles/activities of the voluntary sector (not for profit) organisations nationally and locally in service providing?

The disability field is over 90% organised and run by the voluntary sector. Only in areas where there are no voluntary organisations active are direct government initiatives are seen, but these are uncommon.

Almost all voluntary organisations are supported financially by government, directly or indirectly. All organisations are independent, as in residential services.

Q20. What are the profiles and activities of families in caring and/or campaigning for people with learning disabilities?

Families are either the primary care givers and as such supported by professionals (social workers and/or specialists employed by one of the care providers) or are represented in the board of care providers or are represented in client panels. These 3 roles can of course be combined, and are not mutually exclusive.

In an unofficial capacity, family members may be active as volunteer in the day to day activities as well and as previously reported, parent run organisations also provide some services.

Q21. What are the legal and funding relationships between national government and local administrations and/or service organisations in learning disability?

Through tax revenue, Central Government funds the AWBZ, the special health insurance. Through regional Care Offices (Zorgkantoor) the funds are distributed to service providers on the basis of agreement on production (days service users are present) and various initiatives. The Care Office (Zorgkantoor) plays an important role in innovation.

Q22. How does national (central) government policy and/or legal frameworks impact upon local administrations (government) and service (providing) organisations?:

The impact of National Government on the factual care and support of people with learning disabilities is small and always indirect. The influence is distributed through and diluted by funding channels and these channels go trough local Care Offices, so there is extended accountability from Central Government, through intermediate bodies to services themselves. Certain values are stimulated by supporting certain

projects but the professional organisations themselves (especially the 'umbrella organisations' which are much more inspired, effective and systematic in this respect.)

SECTION 7.   SWEDISH PARTNERSHIP
(UPPSALA-LIDINGÖ)

Kent Ericsson

7.1.   PRODUCT 1 – LOCAL PARTNERSHIP PROFILE

Q1. Describe the relationship between the local administration (local government and/or public sector organisations) and the national state in terms of centralisation-devolution

This is culturally and politically inappropriate form the Swedish experience. At the national level, Acts of Parliament and regulations are being formed. This makes up the framework for what is to take place in disability services at municipal level. At this local level services are financed by local taxation, decided upon by the local parliament. Local services will therefore have local characteristics.

Q2. List and describe the local service (providing) organisations included in the partnership and the services they provide

It is the organisation for disability services of Lidingö which is part of the partnership. They organise and run disability services themselves. Their main task is providing support through housing and daily activities.

Q3. List and describe any other local services providing organisations and the services they provide

A private organisation runs housing with support for three groups.

Q4. List and describe the local administrations (local government and/or public sector organisations) included in the partnership

The administrative body of Lidingö which is involved in this partnership is the Department for the Elderly and the Disabled.

Q5. List and describe the other local administrations relevant to providing services used by people with learning disabilities

A person with an intellectual disability has got the same rights as other citizens to use the services of the Swedish welfare society.

Q6. Specify the relationship/links between the local academic institution or department and the local administration in the partnership

Kent Ericsson is researcher on Disability and Support at the Department of Education at Uppsala University. He is connected to STEPS/Lidingö project partnership on the basis of a project agreement.

Q7. Specify any other relationships the academic partner has with the local administration or local service (providers)

Kent Ericsson has previously been involved in projects with the disability services of Lidingö. He also has had held minor conferences for staff and families in Lidingö.

Q8. Outline and specify the information members of the local partnership hold on the numbers, characteristics and needs of the people with learning disabilities

The local partnership has got full information on persons who receive disability support from this organisation and the services they receive.

Q9. Outline and specify the information members of the local partnership hold on the costs and resources associated with local services/service models/supports for people with learning disabilities

The local partnership has got full information on costs and resources relating to disability services.

Q10. List and describe the service user groups or organisations working with the local partnerships and their activities

Two reference groups are attached to STEPS/Lidingö. One is made up of staff, families and representatives who are involved in the project. The other group is made up of people with a disability and their representatives.

7.2.   PRODUCT 2 – DESCRIPTIVE QUESTIONS COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

Q1. What service planning arrangements or strategies operate at the local (partnership) level and how are service users involved?

The local administration of disability services has one function for economy and another for the delivery of services. In the process of planning for the budget of coming year, the needs of persons are identified. At the same time economic resources are identified. A negotiation process is carried out leading to a decision by the administration for suggested services and budget for the coming year. This suggestion is brought to the political board responsible for disability services. This board decides on a suggestion for a disability programme for the coming year to bring to the local parliament. The decision of the local parliament for the activities of coming year is a final decision. This process takes the major part of a year and is open to influence by citizens.

Q2. What individual (person-centred) service planning arrangements operate locally and how are service users involved?

A formal request from the person and their representative is the starting point of the person's services. Their request is received and a decision is made to accept of decline the request. This procedure can involve a considerable discussion, even negotiation. Once the person has got a positive decision, they receive the services applied for. In the delivery of these services, an informal relationship between the person and the service organisation is the basis for the development of this service.

Q3. How (in what ways) does the local administration (local government) work together with the local service (providing) organisations?

See question 1.

Q4. How do the different local administrations (acute health care, social care, education, housing etc.) work together with each other?

These are all independent bodies and cooperate when the need for this is identified.

Q5. What are the eligibility/legal criteria for access to learning disability services nationally and/or locally?

When a person has got difficulties to manage their everyday life because of a learning disability, they are eligible for support, if this is requested.

Q6. How integrated are services for people with profound and multiple learning disabilities (PMLD) with services for people with learning disabilities more generally?

Services are provided for people with learning disabilities, irrespective of the type or degree of need for support.

Q7. How integrated are services for people with challenging behaviours with services for people with learning disabilities more generally?

See question 6.

Q8. What types of advocacy arrangements are there for people with learning disabilities locally and which are the most inclusive?

a: The person, together with their representative, can lodge a complaint through the levels of the administration of the disability service.
b: The person, together with his representative, can lodge a complaint directly to the political board responsible for the disability services.
c: The person, together with his representative, can lodge a complaint to the provincial administration, that is the local body of the national level.
d: The person, together with his representative, can lodge a complaint to the national Judicial Ombudsman.
e: The person together with his representative, can lodge a complaint to the national Disability Ombudsman.

Q9. What complaints or appeals procedures for service users operate locally and how well do they work?

See Question 8. There scope of complains procedures and channels is comprehensive.

Q1O. What service models for learning disabilities are being promoted nationally and/or developed locally?

This is not culturally appropriate in the Swedish experience. The task is to offer a person with a learning disability a normal life, that is the life lived by others in the community to which they belong to. This life is the life seen as desirable by the person for themselves. The person has got the possibility to use all the welfare services offered by society. The basic motive for this is that the person, irrespective of their degree or kind of disability, is seen as a citizen with the rights and obligations belonging to citizenship. Naturally, the person can not be put in an institution as these have been closed.

Q11. What is the national and/or local evidence of a relationship between different service models and costs?

If quality issues are brought into the equation, community based services are known to be cheaper and more effective in terms of quality than institutionally based services.

Q12. What are the staff training and staff development programmes and priorities within local service (providing) organisations?

No formal programme exists. When needs or when good opportunities arise, staff conferences are organised, so there are various opportunities for dissemination of best practice and exchange and discussion of experiences.

Q13. What national and/or local requirements exist for specialist or professional qualifications within learning disability or social care?

No formal requirements exist.

Q14. What is the extent of the development of the social care market nationally and/or locally?

No social care market exists or is deemed to be required.

Q15. What are the contractual and/or funding relationship between local administrations and service (providing) organisations?

See question 1.

Q16. What are the arrangements for care standards and inspection (regulation) exist nationally and locally?

There is the possibility for inspection from the provincial administration.

Q17. To what extent is cost information individualised in relation to services received by people with learning disabilities?

The costs of a service are related to the needs of the person(s) using this service. Also, see question 1.

Q18. What are the arrangements for direct payments (personal budgets) to people with learning disabilities themselves?

A person with an extensive need for support can receive personal assistance. This is a sum related to their need for support. With this sum they can employ personal assistants.

Q19. What are profiles/activities of the voluntary sector (not for profit) organisations nationally and locally in service providing?

This is not culturally appropriate to the Swedish experience as no voluntary sector exists.

Q20. What are the profiles and activities of families in caring and/or campaigning for people with learning disabilities?

The basic task of the family is to support its member to a good life. This is done mainly as a representative for the person with the disability. Some families are also involved in the parents´ organization (FUB), to work on a general level with disability issues.

Q21. What are the legal and funding relationships between national government and local administrations and/or service organisations in learning disability?

At national level, work is carried out to develop, extend and interpret the disability legislation as expressed in the relevant Act of Parliament. Only occasionally is economic support channelled from national to local levels.

Q22. How does national (central) government policy and/or legal frameworks impact upon local administrations (government) and service (providing) organisations in: 1. social care, 2. health care, 3. learning disability, 4. anti-discrimination.

The municipality has a high degree of freedom to use the taxes decided upon and collected by the local parliament. National regulations form a framework within which to act.

SECTION 8. CATALAN (SPANISH) PARTNERSHIP (BARCELONA)

Isabel Paula

8.1.   PRODUCT 2 – DESCRIPTIVE QUESTIONS COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

National collaboration:

Distribution of competencies in the field of disability

Levels of attention	Field	Competencies
Social Services of Primary Attention	• Basic Teams of Primary Attention. EBASP. • House attention: house help; Tele- alarms, and tele-assistances. Residences of limited staying. • Technical Advice	Municipalities: >20.000 inhabitants: EBASP >50.000 inhabitants: Provide and manage the adapted transport. Provision and management stabilised services through management or delegation. Collaboration in the management of benefits from the Autonomic Community.
Social Services of Specialised Attention	• Support to the Labour Integration SSIL. • Early treatment. • Occupational centres. • Houses provided of Common Services • Adapted Transport	Autonomic Government of Generalitat de Cataluña. Social Welfare Department ICASS. Social Institute of Social Services. Government: General Policy , co-ordination of actions, programmes, evaluation, inspection.
Social Services of Specialised Attention of superior level	Assessment and Orientation. Day Centres of Specialised Attention. Residential Centres.	

Q1. What do service planning arrangements or strategies operate at the local (partnership) level and how are service users involved?

Legislation provides autonomy within Catalonia in relation to social services and provides municipalities with the power to manage primary services, some specialised services, and the overall co-ordination of services within the municipality, with collaboration with the regional administration in resource management and financial support.

The system of social services is structured functionally in two strands – primary social services and social services providing specialised supports. The primary social services operate at the closest level to individual citizens. They are provided through multi-professional teams which carry out the functions of information management, assessment of need, orientation to services and detection and prevention functions. Advice, social and community work are also provided. The teams formulate proposals for gaining specialised social services and apply wider support polices to the services received by individuals, families and groups.

The primary social services are integrated across the following service types:

- Basic primary social service.
- Housing services and supports.
- Residential services of limited stay.
- Meals services.

The specialised social services represent the most specific level of action and support which is addressed to the diagnosis, assessment, treatment, support, and rehabilitation of social problems and needs of individuals and groups. These services are undertaken by specialist professionals and/or community resources, either on daily basis or within residential care.

The specialised social services include:
- Supported and sheltered employment
- Early treatment and prevention.
- Day services and occupational centres for disabled people.
- Group homes.
- Assessment and matching services and support to needs.
- Daily support and domiciliary services.
- Residential care services.

These different centres and services have mechanisms for user participation and follow the principles of normalisation, being provided mainstream and through regular channels and using ordinary resources. The important links between individuals and their families and communities are respected to the highest degree.

Q2. What individual (person-centred) service planning arrangements operate locally and how are service users involved?

At a local level the services provided relate to housing and some leisure related services. At the regional level there are services of early diagnosis and treatment, education, labour and employment services and residential services.

Both primary as well as specialised services place the individual at the centre and conduct person-centred plans of intervention. Primary services represent a co-ordinated set of professional actions. All are integrated by a technical group who work to the objective of promoting the necessary mechanisms to prevent services being needed for individuals, families or social groups, and intervening in cases of high risk or social exclusion.

The goal is to improve the social welfare and advance the integration of people with disabilities, through the following main objectives:
- Containment and prevention in order to avoid a deterioration of the situation.
- Modification, to make or induce the necessary and/or required changes in the situation.
- Prevention, to avoid the development of any problem, and/or conflict, reducing the effects of the deficit or problem and/or the social conflicts resulting, and ensuring the continuity of the intervention.

The specialised services carry out diagnosis, assessment, treatment, support, and rehabilitation of social problems and deficits. These services are performed by specialised professionals and, in some cases, with community resources, either on daily basis or within residential care.

The professional develops a plan for the user, indicating the objectives to be reached and also monitors the process of change and the progress of the user.

Q3. How (in what ways) does the local administration (local government) work together with the local service (providing) organisations?

In Catalonia, most services are provided by voluntary social care organisations and parent's organisations, who develop various service initiatives. These organisations receive financial help from the regional administration.
Co-operation amongst the different administrations generally happens, but not in every case or situation. Providers of services do not depend on the local administration but on the regional administration. Thus, there is a link between regional and local factors and responsibilities.

Legislation on the Social Integration of Disabled People (1982) (LISMI) points out that the provision of social services may be carried out from both the public and private sector, although an emphasis and priority in LISMI is that the public sector must help and collaborate with various providers, especially not-for-profit organisations.

Participation must be related to and reflect public policy, and those organisms that receive public funds must establish mechanisms to promote the participation of the service users and other interests involved.

Art the regional level (autonomous community of Catalonia), the laws related to social services follow the same rules: promotion and empowerment of social initiatives, setting up of channels of participation, the adequate performance of requirements (minimum conditions and standards, authorisation, Registrars, inspection etc,) and relevance of providing procedures to public policy.

Q4. How do the different local administrations (acute health care, social care, education, housing etc.) work together with each other?

The complex administrative system in Catalonia and in the municipalities sometimes makes inter-agency collaboration difficult. The system does not depend on the local administration but rather on the regional system. There are good intentions to collaborate but in reality this is not easy. To date few examples of inter-agency or organisationally transverse programmes have been carried out.

From primary to specialised services, social services are co-ordinated with the rest of the public social welfare sectors (health and education). This partnership is conducted under the principles of normalisation and permanency in the environment, as far as possible. Most of the laws relating to social services point out the need for greater co-ordination and joint working between the health and social care spheres, with the objective of offering a global or holistic service and achieve the most effective and efficient utilisation of resources.
There are however dual social and health care centres for temporary stays and for long term residence available for people who require such service integration on the ground.

Q5. What are the eligibility/legal criteria for access to learning disability services nationally and/or locally?

In order to gain access to specialised services for disabled people, it is necessary to have a Certificate of Disability, which is a document issued by the Social Services department of Generalitat de Cataluña. This document proves the type and degree of the disability and provides the basis for eligibility.

The fact that the national Spanish administration has in recent years transferred political and administrative competencies and responsibilities for social policies and social services to the different autonomous regional administrations has tended to lead to the development of a wide variety of policies and provisions at the regional as opposed to the national level. Only the pension system remains nationally administered and controlled.

In order to gain access to services it is necessary, apart from having a certificate that proves that the person is disabled, to have undergone a system of assessment and allocation. In the case of labour or occupational affairs, this service is called 'evo-labour'. The administration states what type of service is the most suitable: a special job centre, Soi or Coi. Housing is dealt with in a similar way. The procedure states what type of house is the most suitable, and what type of support is required. There is always the possibility of turning to a private service, but for most people this is not an option because their private resources are limited. The subsequent step is to make a proposal to the centre, which can in turn be accepted or refused. This inflexible arrangement effectively means that next to nothing is left to user choice.

The primary services are universal and include:

- Services to support labour integration, targeted on disabled people of working age.
- Services of early treatment, targeted on children with developmental problems or who are at risk and who are under four or over six years of age.
- Occupational therapy services and occupational services for inclusion, targeted on disabled people of working age who have not achieved inclusion in the labour market.
- Housing with common services for disabled people, comprising two components:

a. Residential homes with support services for disabled people who through reduced capability and autonomy are unable to develop the skills required for the routine activities of daily living and consequently require technical, personal or community support for effective participation in daily living.

b. Residential homes for disabled people who need a permanent residence or permanent supervision or assistance to perform daily living activities.

- Assessment and treatment services, devoted to the whole population, especially those who suffer from physical, sensory, or psychological disability and their families or legal representatives who are subject to specialised social services provisions.
- Specialised services in day centres for disabled people, for people with serious disabilities who need special attention and support to develop their daily living routines and daily activities and who cannot use any another service from the general educational system.
- Residential centres for disabled people, for those with serious disabilities and who need help and support with normal daily living and activities, and due to family, social, or geographical reasons, are unable to live at home and who consequently need temporary or permanent support.

Q6. How integrated are services for people with profound and multiple learning disabilities (PMLD) with services for people with learning disabilities more generally?

Providers of services have diversified in the types of services they provide. For example, a house of the same organisation may manage and support a residential service for people with deep psychiatric disability or independent living flats in the community with appropriate support tailored to individual needs.

Such services are not integrated but they are different. Primary services are co-ordinated with specialist services for individuals.

Q7. How integrated are services for people with challenging behaviours with services for people with learning disabilities more generally?

They are separate and are not integrated. They are also various scarce and few examples of such services exist. However, as needs are increasingly being recognised they are beginning to be developed as different services by some providers.

Q8. What types of advocacy arrangements are there for people with learning disabilities locally and which are the most inclusive?

Every person with a learning disability has free access to the municipality social services. At a higher level, the person also has access to the Ombudsman. In a case where the Judge considers that the person does not have the capability to consent or make decisions on their own behalf, a guardian will be designated to protect the rights of the person.

Q9. What do complaints or appeals procedures for service users operate locally and how well do they work?

By law, all service providers must maintain a complaints book, as well as a suggestion box for service uses and relatives to record any complains or suggestions. There are is also an Ombudsman service.

Q 10. What service models for learning disabilities are being promoted nationally and/or developed locally?

Q 11. What is the national and/or local evidence of a relationship between different service models and their corresponding costs?

The regional administration, holding information on and with competencies in the field of costs and different service models, has passed a series of laws and decrees about the public prices of services. The problem is not so much price but the scarcity of places in public services and therefore difficulty accessing places when needed.

Services are funded and receive subsidies based on the concrete plans and number of places assigned. The administration approves a minimum and maximum price that the provider of the service can charge to the service user. The price of the service is in many cases discretional and does not necessarily cover the true costs of supporting individual or different needs between different individuals.

Q12. What are the staff training and staff development programmes and priorities within local service (providing) organisations?

Q13. What do national and/or local requirements exist for specialist or professional qualifications within learning disability or social care?

Q14. What is the extent of the development of the social care market nationally and/or locally?

Q15. What are the contractual and/or funding relationship between local administrations and service (providing) organisations?

Usually, the private organisations and institutions born from the Associations of Parents of People with learning disabilities, due to the needs of their association, have developed new services and offered to and agreed with the administration, including financial support. Until recently, the main way services were funded had been through subsidies. It is planned to change this approach through the use of a service agreement or contract.

Q16. What are the arrangements for care standards and inspection (regulation) existing nationally and locally?

The administration that funds and subsidises services has its own methods and procedures for service inspection. In addition to routine and random inspections of services, regulation is also promoted through the monitoring of claims or complaints made by service users, their families or representatives.

Q17. To what extent is cost information individualised in relation to services received by people with learning disabilities?

The system of access to services, either residential or labour, is through the regional administration. This administration scrutinises claims for services and undertakes assessment, deciding on the most suitable service. There follows a proposal to the centre from the administration, and if this latter accepts the proposal, the administration provides the service to the person involved. This allocation triggers payment (by the administration) of the residential place, which effectively follows the individual – like a rucksack attached to the person.

Leisure activities are not contemplated in public policy funding or subsidy, but a system of grants is provided which are discretionary. These tend to be discriminatory towards those people who do not live with their families, since they do not have the right to receive funding. Consequently, if they do, they are not well off – for example, they have no 'right' to go on holiday.

Q18. What are the arrangements for direct payments (personal budgets) to people with learning disabilities themselves?

Direct payments to people with disabilities do not exist. Only in case where the person has the right to funding from the State, and if they fulfils of the requirements for minimum pensions, everybody is required to have a disability equal or above to 65%.

If a disability is assessed as between 33% and 64%, an individual has no right to receive a pension or welfare benefits. In theory, everybody with a disability could access the labour market, but this is something that has been done. In fact the administration has a series of reserved places for disabled

people and offers such places using a system of access, which is equal for people with physical, sensorial and learning disabilities.

Q19. What are profiles/activities of the voluntary sector (not for profit) organisations nationally and locally in service providing?

The voluntary sector undertakes a wide variety and range of activities, with concrete topics for young people and activities demanding a higher commitment for adults.

Q20. What are the profiles and activities of families in caring and/or campaigning for people with learning disabilities?

Q21. What are the legal and funding relationships between national government and local administrations and/or service organisations in learning disability?

The national administration has transferred responsibilities and competencies to the administrations of the autonomous regions of Spain. Local administrations or municipalities have no competencies or responsibilities in this area.

Q22. How do national (central) government policy and/or legal frameworks impact upon local administrations (government) and service (providing) organisations in:

- *Social policy*
- *Health policy*
- *Learning disability*
- *Anti-discrimination*

SECTION 9. GLOSSARY OF TERMS AND SERVICE TYPOLOGIES

Paul Cambridge and Anne Ernst

This element of the comparative framework aimed to help with the development of a shared vocabulary and language in the field of social services for people with learning disabilities and to provide a reverence tool to increase mutual understanding and promote information exchange and dialogue between the five partners (see chapter 1.3.3.).

In terms of process, the partners were asked to present their respective national entries in English. On the basis of the English template, partners were encouraged to include national definitions and specific national terms. The national contributions were completed by information from the partnerships (Sections 4 – 8) and other documents (see reference list). All the information provided was finally integrated into a single glossary before being presented in its current format. For example, previous forms of the glossary including separate national entries which had been used as working and reference documents by the STEPS partners at project conferences.

Similar to the other elements of the comparative framework, the glossary also risked an initial Anglo-German bias. However, a process of consultation and ongoing development, with the construction and refinement of comparative terms and definitions, including the highlighting of national similarities and differences (summarised in Section 3 and Figure 6), again allowed a more analytical and representative framework to develop.

The following guiding principles informed the collation and construction of the glossary:

- Terms were sorted and presented in alphabetical order.
- Specific national terms with no cross-national equivalents are set on their own in italics, with explanations in English.
- Key cross-referencing of terms in the glossary with sections of this report is included where and when it is considered helpful.

It is recognised that the construction of an operational tool such as a glossary is an imperfect exercise and that all such tools need to be developed and refined over with time and with experience. However, our hope is that it will provide the basis for further comparative work within and outside STEPS and that it will aid the development of ongoing cross-national discussion, comparison and interpretation. It should therefore be used in parallel to other such glossaries, for example the one developed by the IDRESNET group (Beadle-Brown et al, 2003). This was in the more simple form of an integrated alphabetical list of the various national key terms used by the project. The STEPS glossary has been built around a more explicit attempt to provide for cross-national comparisons of key terms as well as offering definitions of national terms.

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Accompa-nying Person					*Type of service that can be applied for in Sweden: An accompanying person should give support for participation in community life (e.g. for leisure activities or sports events) for people who live in their family homes.*
Adult education	Education provided specifically for adults. People with learning disabilities have access to adult education in colleges covering a variety of subjects and topics such as numeracy, literacy, cooking and life skills.	In Hamburg, some service providing organisations for people with disabilities offer a joint programme for further education. Officially, people with learning disabilities have access to adult education centres (Volkshochschulen), but due to high barriers they mostly do not join them. Vocational education is part of integration in work. The aim is to maintain or increase vocational competences.	Private organisations manage courses especially for people with learning disability. These organisations are usually special schools or connected to the local department of social work. Increasingly, contacts are established with mainstream education, especially in the field of work training. At present, inclusive education is more common with children than with adults.	Sets of educational programmes designed to promote culture among citizens who have passed compulsory education, with the aim of compensating for their learning disability and to promote active citizenship.	
Advice and support					*Type of service that can be applied for in Sweden: When a person needs support for their disability which is offered through an expert (such as a social worker, therapist or psychologist) they can apply for 'advice and support'.*

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Advocacy See product 2, question 8, of each partner-ship section and chapter 2.3.8	The process of identifying with and representing a person's views and concerns in order to secure enhanced rights or entitlements undertaken by someone who has little or no conflict of interest. In practice advocacy is characterised by diverse paradigms of support and intervention, including legal, professional, citizen, self and peer advocacy.	Although this approach is not especially well-known in Germany, being characterised as 'self-help' groups, there is also an active and developing self-advocacy movement in Germany, with groups such as People First and Autonomous Living.	Social workers, who are not employed by care providers, may be professional representatives and/or advocates. Peer group advocacy is known and stimulated but not very effective. In our opinion service providers cannot be advocates. Parent advocacy is evident through most boards of care providing organisations as well as in day activities, on location (scheme) level and at management level.	Function of guaranteeing and defending the individual rights of people, minorities and vulnerable adult groups. See also Guardianship.	This approach is not well-known or developed in Sweden, partly because current service arrangements provide for the functions advocacy might perform elsewhere.
Assess-ment	A device for assessing someone's eligibility for services. In the UK this is generally a needs assessment for community care services on the part of the service user or the needs of the carer. It is the device which defines individual eligibility and is a statutory responsibility of local government/joint services. It is used to match needs to resources.	A device for assessing someone's eligibility for services.	The word is used in the Netherlands to describe the process of matching needs of the service user to the actual care and support provided. Assessment is the 'indication' that the AWBZ formulates as eligibility criteria before anyone enters any service. See Insurance.	Diagnosis of a case, orientation and proposals for intervention.	A device for assessing someone's eligibility for services.
AWBZ			*Algemene Wet Bijzondere Ziektekosten – general law concerning special health costs.* *See Insurance.*		
Bench-marking	A system of comparing services on a series of comparative measures covering quality and standards and hence performance.	The same as in England.	The same as in England. In the Netherlands bench-marking takes place on a strictly voluntary basis among care providers.	Little developed.	

Best Value	*Central government initiative requiring local authorities to assess services in terms of performance indicators (see Glossary) re. quality and cost and in relation to other similar services provided by other public and independent sector organisations. Independent assessors are employed by central government to assess Best Value reviews from which service improvement plans are put in place.*		Is a term that is not used in the Netherlands. However, due to the permeation of American values, the practice of comparing activities and outcomes and making them public is beginning to take shape between schools, universities and to some degree between hospitals.		
Care in the commu-nity	The specific policy and practice of moving people from institutional care provisions (long-stay hospitals) to community care.	See Community Care.	The same as in England. See Community Care.	See Community Care.	
Care manage-ment	*A statutory requirement of social services departments since the 1990 health and social care reforms. Individual care managers have responsibility for managing a caseload of service users with long-term care needs in social care, such as people with learning disabilities. Operationalised through generic or specialist teams and variously integrated with other professional roles such as social work. Care managers are generally responsible for core tasks such as assessment and individual service planning and review. Caseloads and organisational characteristics vary immensely between authorities.*				

Care market See product 2, question 14 of each partner-ship section and chapter 2.3.2	Developed from the mixed economy of care of the 1980s, where voluntary and statutory (public sector) agencies provided social care services, and introduced as a policy with the 1990 community care reforms alongside consumerism and cost-effectiveness. Characterised by the explicit separation of purchasing from service providing, with local authority social services departments or partnership boards responsible for purchasing from not-for-profit, voluntary and independent (private) agencies through contracts.	The political intention in Germany is for authorities to foster market mechanisms in the field of social work to realise 'service orientation, efficiency, flexibility, more offers, cost effectiveness'. Key words include output-orientation, prospective payment system, introduction of service products, controlling, benchmarking and competition.	See mixed economy.	This term is not generally used in Spain, although some are arguing for the development of care markets.	A care market does not exist or is not deemed to be necessary in Sweden.
	England (London/Canterbury)	**Germany (Hamburg)**	**Netherlands (Rotterdam)**	**Spain (Barcelona)**	**Sweden (Lidingö)**
Care standards See product 2, question 16 and chapter 2.3.9	Minimum standards set for social care service provision across a wide range of criteria established by the Commission for Social Care Inspection and used to monitor and help improve quality and perfor-mance in regular CSCI inspections of services.	Standards set for social care service provision.	The National Authority requires a quality report from all care providers. Factual control is executed through the local Care Offices (Zorgkantoor) who also check the financial aspects of the care provided. See Insurance, see LCIG.	Used at reference level for a performance or quality indicator.	
Choice		*Important value in book IX, Social code, in connection with participation (Wunsch- und Wahlrecht). Regulations should guarantee fulfilment of rights and wishes taking into consideration life situation, gender-related and religious needs and wishes.*			

Commiss-ioning	*Establishing what needs there are, deciding what services there should be and who should pay for them, and getting the right organisation to provide them, usually in relation to local statutory money (for instance, local and health authority money). Commissioning is usually linked to other strategic activities such as service planning and qualitye review.*		See LCIG.		
Commu-nity care	The generic term for social care services which are developed and located in the community as opposed to in institutions (long-stay hospitals or other congregate services segregated from the community). May include residential care models but generally ordinary life models such as supported living.	Non-residential, community integrated services: Opposite of residential services. Non residential services are planned and paid for individually and provided in the person's or the family's home, e.g. 'pedagogical assistance in the person's home' (pbw) or 'housing assistance'. By law, non-residential care should have priority over residential care, in practice this demand is not realised.	The same as in England.	Set of services offered to people and their families without leaving the community (their home) they belong to. In Spain (Catalunya) many of these services are generalise for the whole population. Generic term which comprehends nearby and home services.	The same as in England: housing and daily activities for people with learning disabilities.
Commu-nity (learning disability) team	A multi-disciplinary team of professionals working together to support people with learning disabilities living in the community services or with families or informal carers. Support is also usually provided for staff and carers.		The term as such is not used in NL. The activities mentioned in the English text are practised both within the care providing organisations as with external, independent agents. These agents may work on regional and provincial levels as well (Consultation Teams).		
Contact Person					*Type of service that can be applied for in Sweden: To guarantee a social relationship for someone the contact person has the task of being a 'paid friend'.*

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Contract	A (generally) written and signed legal device for agreeing the provision of services and payment for them. In health and social care in the UK the contract is the formal device for defining the legal relationship between commissioners and service providers. Individual contracts are possible through individual funding and direct payments, although other types of contract such as block and cost and volume contracts are also utilised.	Framework contract: According to § 93 Federal Social Assistance Act the Social Assistance Agency (in Hamburg the Ministry for Social Welfare and Family) concludes a framework contract for services with the associations in the voluntary welfare sector and private provider associations. The contract stipulates the general questions of payment, content of services, quality management etc. Service Agreement: The local Social Assistance Agency (in Hamburg the Ministry for Social Welfare and Family) concludes a service agreement with each service providing organisation covering the content, extend, quality of services etc.	The care providers have contracts with the Health Insurance Offices (Care offices: Zorgkantoor) who execute the special law AWBZ. See Insurance.	Agreement between the finance agency and the service providing organisation in which the conditions of the service, such as rights, responsibilities and duties are specified and settled.	
Day centre	A centre providing day services and support, generally located in the community, with an emphasis on developing social skills, integration and outreach, rather than adult training.	The same as in England.	The same as in the UK. In the day centres in the Netherlands, training on the job programmes are used and often day centres work together with enterprises in the profit sector. See supported employment.	A centre providing day services and support.	

Day services	Special services and support for people during the day, provided either at home or in or from day centres.	Education and occupation offered in a day centre for people who do not work in a sheltered workshop or at the first labour market. People with severe or multiple disabilities are supported with pedagogical measures (Part of Integration Assistance).	The same as in England.		Adults who do not get employment can receive support during the daytime through daily activities with support. Day activities are organised in the community.
Disability	The definition most commonly used is included in the Disability Discrimination Act 1995. This identifies 'disability' as: • a mental or physical impairment; • having an adverse effect on the person's ability to carry out normal daily activities; • the adverse effect is substantial; • the adverse effect is long term ie more than 12 months.	People are disabled if physical functions, mental abilities or psychological health differ from the characteristic condition in an age group probably for more then six month and thus participation in society is restricted not only temporary. (Definition of Book IX Social Code – Integration and Rehabilitation of Disabled People, according to the definition of the World Health Organisation).			

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Discrimi-nation	Direct discrimination Direct discrimination occurs when a person is treated less favourably than another in a comparable situation because of their racial or ethnic origin, religion or belief, disability, age or sexual orientation. However, in reality discrimination often takes more subtle forms, which is why indirect discrimination is also covered. Indirect discrimination Indirect discrimination occurs when an apparently neutral provision, criterion or practice would disadvantage people on the grounds of racial or ethnic origin, religion or belief, disability, age or sexual orientation unless the practice can be objectively justified by a legitimate aim.				

Direct payment See personal budget, see product 2, question 18 and chapter 2.3.10	A direct payment or 'individualised funding' to service users or their representatives, from a social services department. Direct payments cannot be used for permanent residential care or any health care.	The same as in England. Not implemented comprehensively but encouraged with the German Social Law. (At the moment Hamburg carries out a pilot project with 100 people.)	The same as in England, but generally called personal budgets. 20% of the users receive a personal budget.	Does not exist in Spain.	Users with extensive needs can apply for individualised funding for personal assistance.
Diversity	The presence or representation of a range of different characteristics in a population, such as ethnicity, race and culture, age, ability and disability, sexual orientation and gender.				
Eligibility criteria See chapter 2.3.5 and product 2, question 5.	There are no legal eligibility criteria for access to learning disability services in England or the UK. Primary access is through a local authority needs assessment, with access varying from one local authority to another based on local priorities and resources. This leads to local inequities. Where there are legal entitlements such as to education or medical care, learning disability is not specified.	All people with disabilities or at risk of becoming disabled are entitled to rehabilitation benefits (definition of disability according Word Health Organisation). For people with severe disabilities, the local pension office determines the level of disability and makes out an official notification. If the level of disability is at least 50 percent the person is entitled to special benefits.	The same as in England.	People with disability need a Certificate of Disability, which is issued by the regional Social Service Department. The document proves the type and degree of the disability and provides the basis for eligibility.	When a person has got difficulties to manage their everyday life because of a learning or other disability they are eligible for support.
Employ-ment	Paid work/labour. For people with learning disabilities this may be in mainstream employment, through supported employment or special sheltered work projects. Paid employment in the UK may effect the benefit entitlements available for people with learning disabilities.	Sheltered workshop: Organisations of occupational integration, offering vocational training and jobs for people who are permanently or temporarily unable to find employment on the open job market due to their disability. Employment Assistance: Assistance for people with severe disability to participate in employment in the open labour market; to find or maintain an employment position.	Besides the first (profit), a second (government) and third (not-for-profit) labour market exist. In the NL there are organisations which do not fit into any of these three categories, such as some social enterprises which receive public funds in order to address people distanced from the labour market, such as people with disabilities. They try to create new jobs and find economic niches. A social firm is an independent, private organisation, partly depending on subsidies and partly generating its own income.	Supported employment and special sheltered workshops.	A priority is given to people with learning disabilities participating in mainstream employment. Some special employment projects have been constructed. Adults with disabilities who do not get employment are entitled to daily activities with support.

Empower-ment	Providing people with the power (by various means) to make their own choices and decisions in order to help affect the positive changes they want in their own lives.				
	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Equality/ Equal-isation of opportu-nities	The notion that people are treated equally (e.g. have the same eligibility/access to services) regardless of other characteristics such as gender, culture, race, sexuality, age and so on. The term 'equalisation of opportunities' represents the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities (UN-Standard-Rules).				
Equity	The notion that people are treated fairly according to their level and type of need (e.g. those with most needs get the most intensive or frequent service).				
Gover-nance	The process of guarding the values and purpose of the organisation, for example through qualifications, supervision, etc., setting direction and policy, acting as a final process of appeal for internal disputes and overseeing management, but not getting involved in day-to-day matters.				
Group home	A house in the community where a small number of residents live together with staff support, developed in the 1980s and 1990s with de-institutionalisation and linked to Ordinary Life principles.	Living facility for a smaller number of people with disabilities in the community linked with residential services. Group homes try to strengthen self-determination and participation in daily life in the frame of residential services.			Group home for children: Type of service that can be applied for in Sweden.
Guardian-ship	A legal term for someone being under the guardianship or protection of the courts or a person elected by the courts who has powers to act in the person's interests.	Guardianship law (1992) aims at protection of people who cannot represent themselves in a way that guarantee as much self-determination as possible. The represented person has to be involved in every decision. The guardian (a person or a guardianship association) is authorised and controlled by court.	The same as in England.	The Civil Spanish act (1983) enables not-for-profit entities to perform as guardians. Guardianship is available for all people with learning disabilities who have no family or for those whose families do not support them. It covers the basic needs of the people, such as, food, housing, job, leisure, as well as administering their patrimony for their exclusive benefit, defending their rights, and striving to offer them the best possible quality.	
Health care	Medical and nursing care, primary health care through general practitioners (GPs) and acute hospitals.				
Housing support		Assistance for independent living in the own home (pbw): type of non-residential community based service in Hamburg.			Type of service that can be applied for in Sweden. It is for adults who have left the family home for a home of their own.

Inclusion	Being part of a broader set or group of interests and having a stake in and participating in society – hence the term social inclusion for people with learning disabilities. Can be used as a policy aim as in England for the broader inclusion of people with learning disabilities in mainstream society.				
Informal care	Unpaid care provided informally by partners, family members, relatives or friends. Carers may be entitled to certain benefits or support from the national or social services.	The same as in England.	Informal care is referred to as Mantelzorg in NL: not-professional-carers who care. A literal translation of the word Mantelzorg would be: helping someone (with basic things like) putting a coat on.	It refers to 'informal carers', although the term 'voluntary attention' is preferable in Spain.	
Institution	Traditionally used to describe a large long stay (mental handicap or psychiatric) hospital, but also used to describe any organisation or service which is rigid or fixed in approach with an 'institutionalised' culture or characteristics, such as being inward looking.	In contrast to the UK, the term traditionally describes any big organisation, foundation or entity, such as the voluntary welfare organisations in Germany which provide serviced for people with disabilities. It hence has a less negative meaning and connotations than in England.	The concept *institute* has in general in the NL a less negative ring than in the UK or Sweden, being used as a more neutral term.
The term institute is consequently equivalent to *organisation* in English.
An institute is not necessarily a big building and may well be an organisation with small scale facilities. A sentence like 'the self advocacy movement is a good institute' will not raise any eyebrows in the NL.	In Spain, this term has a double meaning: the less common is the one used internationally (closed organisations or large congregate residential facilities). The other refers to any organisation, foundation or entity, as in the NL.	The same as in England.

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Insurance	National insurance is paid by wage earners towards state retirement pensions and health care. Private medical and other forms of insurance can be taken out individually.	Most life risks are covered by insurance which are financed half by the employer and half by the employee: Statutory health insurance, statutory long term care insurance, statutory pension insurance, statutory Accident Insurance, unemployment insurance, see Social Code Books. Due to the fact that most people with disabilities are not entitled to insurance benefits, most benefits for people with disabilities are covered by the tax-financed Social Assistance. See welfare benefits.	The AWBZ is the general law concerning special health costs (covering 90-90%). It is the legal basis of the financing system for health care and social welfare, including services for people with learning disabilities. All Dutch citizens pay a certain percentage of their taxes to keep this law functioning. Within the AWBZ 7 modules are distinguished: 1) household support 2) personal support 3) assistance in normal living arrangements (in 3 variations, one of these being transport , another one being respite care facilities) 4) (support in) day activities (in two variations, one of them being transport) 5) nursing (medical assistance) 6) treatment 7) residential care – stay facilities (two variations: long term and short term stay, like crisis intervention). The package of services users are entitled to is set by the LCIG, an independent body.	Social services fund most of care and programme interventions for people with learning disabilities from work taxes.	Services for people with learning disabilities are primarily funded by local taxation.
Joint Commis-sioning	*The process of establishing a joint purchasing strategy for services, through bringing together the budgets of two or more organisations.*				

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Joint invest-ment plan	*The financial planning mechanism developed by partnership boards for the services for a particular user group, including for people with learning disabilities. Subject to outside review by Government regulatory/inspection agencies.*				
Joint-team	*A community or specialist multi-disciplinary team developed and organised jointly between health and social services with professional representation from both agencies (e.g. nursing and social work).*	The same as in England.	Locale Zorgnetwerken (local care networks): A community or specialist multi disciplinary team developed and organised jointly between health and social services with professional representation from agencies, the local police force, social psychiatric nurses (spv-ers), representatives of the building co-operation etc.	Not particularly developed in Spain. It refers to an inter-agency team (for example, health and social services). See multi-professional team.	
Joint working	*Strategic service development work and planning between two or more public sector agencies, usually health and social services in the UK. Developed in the 1970s and 1980s through joint finance and now executed through explicit partnership working.*	Joint Service Centres: Key feature of Book IX, social code. Established by the social assistance agencies, the service centres act as points of contact in each administrative district and offer comprehensive help and advice independent of any specific fund or provider.	Strategic working and planning between private social enterprises (charities) on social issues (services and support). The public sector may play a role but more often than it does it does not. Local administration encourages joint working without participating in it.		
	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Key worker	A support worker who has special responsibility for working with and supporting a particular individual (service user). Key worker systems are widely used in the UK although key working is not exclusive from the wider support of other service users.	The same as in England.	As in the English context. Usually referred to as PA (personal assistant) in NL – the term 'key worker' is less commonly used.	Not a used term or relevant concept in Spain..	

LCIG (Landelijk centrum Indicatie Gehandi-capten)			*The national commission which is locally organised, deciding in which of the 7 categories the applicant for care a/o support fits, or what combination of 7 categories must be made.* *LCIG is an independent organisation and has as such no financial ties with any government administration nor any care provider.*		
Learning Disability	Previously 'mental handicap' in the UK but also 'mental retardation' (US and Canada) or 'intellectual and developmental disability' (Australia and New Zealand). Not to be confused with 'learning difficulty' which refers to specific learning difficulties such as dyslexia (although the term learning difficulty is still preferred by some self-advocates with learning disabilities). *Valuing People* defines learning disability as having 'started before adulthood with a lasting effect on development' and with a significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), and with a reduced ability to cope independently (impaired social functioning).	Related to the English term 'mentally handicap', in Germany the term 'geistige Behinderung' is widely used. Self-advocacy groups promote the use of the term 'learning disability' (Lernschwiergkeiten). People with learning disabilities are not a group with determined or set characteristics. Central characteristic are significant learning disabilities, caused for example by brain impairment or brain function disturbance, with differentiation between mild, moderate and severe learning disability, similar to more technical definitions used in the UK.	In the NL, as explained in the English text, there are different terms used. Currently the notion is that *Learning Disability* is a term that would be replaced by *Intellectual Disability* (Verstandelijk Gehandicapten), which is more commonly used in Dutch.	The term mental retardation (Retraso mental) is common in Spain.	

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Leisure support					*Type of service that can be applied for schoolchildren over the age of 12 in Sweden: If the parents are not at home when the school day is finished or in holiday the child can receive leisure support which takes place outside of the home.*
LISMI				*Legislation on Social Integration of Disabled People (1982): national framework for services for people with disabilities.*	
Main-stream services	Ordinary services available to everyone, such as education and health care rather than specialist services available to a particular user group, such as services for people with learning disabilities. Hence the use of the terms specialist (segregated) or mainstream (integrated) education for people with learning disabilities. See chapter 2.3.6.				
Mixed economy See product 2, question 14 of each partner-ship section and chapter 2.3.2	Having a number of different service providers, such as public sector and voluntary, rather than all services being provided by the public service agencies or through a more explicit care market with a number of private, not-for-profit/voluntary and public sector providers operate in a more explicity competitive environment.	The same as in England. In Germany most services for people with learning disabilities are provided by voluntary welfare organisations.	Having a number of different service providers is the normal situation in the NL. It is rare that all services are provided by one service agency and even rarer when this is a public service. The mix in the economy takes place between the voluntary sector (the not-for-profit-sector) and the profit sector. The public sector is a small player in our field and very specialised in its services and not active in what we understand by mixed economy. There is no principal reason why public services are not 'mixing'- it is simply established practice.	In Spain public sector, not-for-profit and private sector organisations operate in a limited mixed economy.	Services are primarily provided by public service agencies in Sweden, making notions of a mixed economy or care market irrelevant.
Multi-professio-nal teams	See multi-disciplinary and joint teams.		See joint team.	Provides primary social services: information, assessment, community work, detection and prevention.	

Normali-sation	The right of people with learning disabilities 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 disability is to live a normal live, with the support from the general welfare services. This became the starting point of the de-institutionalisation process in Sweden and other countries (see references Nirje, 192; O'Brien, 1987; Wolfensberger, 1972 and 1992).			
Nursing	A particular professional orientation within a tradition which aims to meet the medical and health needs of the individual using a medical model. Learning disability nurses used to work in the long stay hospitals in the UK and are now an important role on community teams or in specialist care management teams.	Medical and health needs are covered by the statutory health insurance and statutory long-term care insurance. A person in need of long-term care requires relevant assistance in daily life-activities in the fields of personal hygiene, feeding, mobility, house keeping, provided by the service providing organisations.	The same as in England.		
Office for Non-Discrimi-nation				*The Office for Non-Discrimination (OND) was inaugurated in December 1998, in response to a growing demand for information from citizens. This is the first municipal office of its kind in Europe, and its function is to defend the rights of people and groups in Barcelona who are discriminated against for reasons of gender and sexuality, membership of a cultural group, physical and mental health problems and age. The OND offers information, legal advice, mediation in disputes and work in the fields of identification and prevention of discrimination.*	

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Ombuds-man See product 2, question 8, of each partner-ship section and chapter 2.3.8	In the UK, the local government ombudsman (national office) has a brief/remit to judge and deal with complaints made by members of the public concerning mal-administration in local government.	The (National) Ombudsman for interests of people with disabilities represents the interests of people with learning disabilities within the government, influencing political decisions and legislation and is the contact person for people with disabilities in the government. Responsible for public relation and lobbying. Hamburg: Senate's Coordinator for Equality of people with disabilities (same tasks as the national Ombudsman but on a regional level).	In the Netherlands the Ombudsman is a national institute. The institute deals with complaints from the public concerning mal-administra-tion by any public body and/or official. In the disability field the Ombudsman would never give a reprimand or advice without having consulted the Federation of Parents organisations. Apart from the Ombudsman institute all care providers have a 'protocol of complaints' which states that when there are complaints or disagreements external experts may be called upon, free of costs. The local care providers are therefore rarely addressed by the Ombudsman.		The Office of the Disability Ombudsman was established in Sweden in 1994 to monitor issues relating to the rights and interests of people with disabilities. The Ombudsman works to achieve the general objectives of disability policy – full participation and equality. The Ombudsman's activity is regulated in a special statute. The Disability Ombudsman seeks to remedy legislative deficiencies and to raise the issue of statutory amendments, etc. The Ombudsman offers legal advice, he co-operates with organisations representing and run by persons with disabilities. The Swedish Ombudsman model has been widely replicated elsewhere.
Outcomes	The impact or effect on people and the environment – the differences that a project really makes. Outcomes may be difficult to measure and are often contrasted with output, which tends to stress things you can easily count, such as numbers rather than quality of life or satisfaction. Intermediate outputs are things like staff skills and final outputs are things like improvements in a service user's quality of life.				
Partici-pation	Broadly, participation is taking part in something and in learning disability generally referes to service users being involved in making decisions about services and their lives. Equal participation in society (as the positive contradiction of exclusion) aims particularly at people 'being present in reality', legal participation and participation in decision-making are other specific approaches.				

Partner-ship Board	*Partnership Boards (for each service user group) define the working relationships between RBKC Social Services Department and K and C Primary Care Trust. Such boards exist between all social services departments and PCTs but their representation and coverage varies widely.* See user advisory board.	In the frame of the equality law for people with learning disabilities the Hamburg Ministry for Social Welfare and Family plans to establish an advisory council of people with learning disabilities as the federal government and some states have already done.	See user advisory board.	
Perfor-mance indicators	Indicators that provides a way of measuring or assessing how well an organisation is 'performing' so that it can be compared with others or with past achievements. They often become tied up with targets and bench-marking. They are a key part of Best Value (see Glossary), and are used by many central and local governmental agencies and may also be linked to minimum standards.	The same as in England.	Productiedagen: The English definition is relevant to the Dutch situation, although the term used for this activity would be benchmarking. The hard performance indicator is the number of days the client is in care. The production (expressed in the total number of days is set in agreement between the care provider and the Care Office (Zorgkantoor) on a yearly basis. The quality of care is the second aspect of performance indicator next this financial (production) aspect.	The same as in England: Provides a way of measuring how well an organisation is 'performing' so that it can be compared with others or with past achievements.	

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Personal assistance		Support which enables the person to live more independently or with relative autonomly – paid by personal budget. The person acts as a self-determined subject ('employer') instead of being treated as an object, decising about the assistance they need and get and the necessary support to live a normal life according to their wishes and needs. In concrete terms, the person decides about staff, time, place, aim of assistance and the particular provider.			People with an extensive need for support have the possibility to apply for personal assistance. This is a resource received by the person and their representative. With this it is intended that the person can employ personal assistants who will provide the support requested. In this way the person can live in their family home or in housing chosen by themselves. The assistants come to their home, where assistance is given and when required.
Personal budget	A budget for the services received by an individual service user or a budget devolved to an individual worker to purchase services. See direct payment and product 2, question 18 and chapter 2.3.10				
Person-centred planning/ Personal planning See product 2, question 2 and chapter 2.3.4	Planning individual services in a way which is centred on and organised around the individual through their participation and expressed wishes.	Service Planning: Together with the person with disability the local Social Assistance Agency should draw up a General Service Plan for each user. The plan forms the basis for the detailed service planning of the service providing organisations. The service providing organisations implement in-house service planning instruments to plan and monitor services individually. The person with disability should participate in the process.	Every service user has an individual service plan which is updated annually at a minimum. Personal Future Planning and PATH planning are used facilitatively.	Primary as well as specialised services draw up a person a person-centred plan of intervention.	In Sweden, an informal relationship between the person and the service organisation is the basis for the development of services. A method of personal future planning for people with learning disabilities is called the seasonal meetings (see chapter 2.2.4.)
Pro-fessional qualify-cations	The qualifications required to be part of a particular professional group or to practice as a particular professional, usually awarded from a professional body or through an accredited course. See product 2, question 13 and chapter 2.3.11				

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Pro-spective payment system		The service providing organisation charges and is paid, according to the number of service users it provides services and support for. Although funding is therefore notionally on a individual user basis, costs are not adjusted to individual needs or individual service utilisation, so are effectively aggregated.			
Purcha-sing	The function of purchasing services for people with learning disabilities (or other groups), hence service purchasing agencies such as social services departments or purchasing through partnership boards and joint commissioning arrangements, through contracts or service agreements with service providers.				
	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Quality manage-ment	A system to manage and improve quality, mostly through quality audit systems and arrangements.				
Rehabili-tation		A process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.			

Relief				*Type of service that can be applied for in Sweden: A family will sometimes need support so that they can engage in personal or family matters away from the task of caring the person with a disability. This type of service can be offered in or outside the family home.*
Residential care	Generally used to describe care provided in residential homes, as opposed to nursing homes where a health care element is provided in situ. Generally a more congregate form of service provision compared to group homes for example. The 'residential' component of a service package or service costs is sometimes used to describe housing and hotel costs.	Originally institutional services in the traditional big centralised institutions. Today residential services are offered as well in group homes in the community, run by the service providing organisations. Services are provided 24 hours a day and organised according to the needs of the group, with institutional funding.		Does not exist in Sweden.
Risk management	A strategy for assessing and then managing or reducing risks for the person and also maximise benefits and opportunities.			
Self-determination	The capacity of someone to determine their own life and destiny.			
Service providing	The function of providing services for people with learning disabilities (or other groups), hence service provider organisations or different services providing different parts of someone's service package.			
School education	Education provided in a mainstream or special (learning disability) schools. Integrated education is through mainstream schools and special education in special or segregated schools.			
Self advocacy	Advocacy provided by people with learning disabilities themselves, usually through self-advocacy groups and self-advocacy organisations like People First.			
Severe learning disability	Mild, moderate and severe learning disability are terms used to describe the general level of learning disability developed originally from IQ levels.	Severe disability: If the level of disability is at least 50 percent the person is severely disabled (see 'determination of disability'). He/she is entitled to special employment protection provisions and special benefits to compensate disadvantages (tax concessions, free public transport, etc).	Same as in England.	

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Sheltered Work/Employ-ment	See Employment.				
Social care	Care for social needs and of a social nature for groups such as older people, people with learning disabilities and people with mental health problems, as opposed to health (medical and nursing) care.				
Social Code		*The social code determines the German Social Welfare system. It is laid down in the different social code books which include different services and finance systems. Social Code, Book IX – Integration and rehabilitation of people with disabilities came into power in January 2001. It codifies and consolidates the law applying to various benefit sectors The focus is self-determination and equal participation and elimination of barriers to equal opportunities of people with learning disabilities.*			
Social Pedagogic	Not a term used in the UK, but the closest definition is social work.	*Social Pedagogic, Social Work: Historically Social Pedagogic has described an academic education which aims at an extracurricular education process in the direction of self-determination. Today there is no difference between Social Pedagogic and Social work (= service for the welfare and self-fulfilment of human beings).*	Specialist in social sciences, more precisely in (special) education. Education counsellor. In the disability field Ortho Pedagogues are employed by (almost) every care provider or used as consultants.	In Spain the academic education is called 'Educational science'.	

	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)
Specialist team	A (usually multi-disciplinary) team of professionals specialising in providing support for families, staff and service users in a particular area of needs, such as challenging behaviour (community support team for people with learning disabilities and challenging needs).		Consulenten team: The word specialist is commonly used in the medical sector. In the Netherlands the word in the disability sector would be *consultant/advisor*. The consultants team is a multi disciplinary body with social workers, an ortho-pedagogue and a psychologist (for example).		
Support worker	A paid worker who provides direct support for service users.		The same as in England.		
Supported employ-ment	Providing support, through outreach or special schemes, for people with learning disabilities to enter mainstream employment. Sometimes undertaken in conjunction with particular employers, with enhanced support in the workplace.	See employment.	In the NL the word is also used and applied to voluntary work (work without pay). A job coach may well support clients in mainstream employment in earning wages.		
Targeting	A device, based on considerations of equity, to help ensure that services and resources are redistributed according to needs (e.g. vertical targeting to ensure services get to people with particular needs in a population and horizontal targeting, to ensure services get to people with similar needs in different populations or localities)		Not a term used in the Netherlands, but the actions which are described in the English text are executed here as well. This is the task of the ortho-pedagogue and the Specialist Team in close cooperation with the family of the service user and representatives of the care provider. MRIC and SZR are tools for targeting; measure instruments.		
	England (London/Canterbury)	Germany (Hamburg)	Netherlands (Rotterdam)	Spain (Barcelona)	Sweden (Lidingö)

User advisory boards	*See partnership board.*	Statuary user advisory boards exist in sheltered workshops and service providing organisations.	Every service providing organisation has to have its own Client board. They have influence on strategic decisions and day to day activities and they are very successful.		
Welfare benefits	The different state benefits people are entitled to receive depending on their personal, family and financial circumstances. Some are assessed (eligibility means tested) locally, such as housing benefit whereas others are accessed through local offices of the department of Social Security (Benefits Agency), such as disability living allowance, attendance allowance and mobility allowance.	Social Assistance: According to the Federal Social Assistance Act (BSHG) the tax financed social assistance provides support for people in needs who cannot help themselves. Men and women with disability receive integration assistance to foster medical rehabilitation, participation in work and society. Although social insurance has priority over social assistance, most people with disability receive integration assistance because they are not entitled to insurance benefits.	See insurance.	See LISMI	

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APPENDIX 1: MEMBERS OF THE FIVE STEPS-PARTNERSHIPS, RESPONSIBLE FOR THE NATIONAL COMPARATIVE FRAMEWORKS

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APPENDIX 2: LOCAL PARTNERSHIP DESCRIPTIVE PROFILES

1. The relationship between the local administration (local government and/or public sector organisations) and the national state in terms of centralisation-devolution

2. The local service (providing) organisations included in the partnership and the services they provide

3. Any other local services providing organisations and the services they provide

4. The local administrations (local government and/or public sector organisations) included in the partnership

5. The other local administrations relevant to providing services used by people with learning disabilities

6. The relationship/links between the local academic institution or department and the local administration in the partnership

7. Any other relationships the academic partner has with the local administration or local services (providers)

8. The information members of the local partnership hold on the numbers, characteristics and needs of the people with learning disabilities

9. The information members of the local partnership hold on the costs and resources associated with local services/service models/supports for people with learning disabilities

10. The service user groups or organisations working with the local partnerships and their activities

APPENDIX 3: COMPARATIVE DESCRIPTIVE INFORMATION COVERING LOCAL ARRANGEMENTS WITHIN THE NATIONAL CONTEXT

Q1. The service planning arrangements or strategies operating at the local (partnership) level and how service users are involved

Q2. The individual (person-centred) service planning arrangements operating locally and how service users are involved

Q3. How and in what ways the local administration (local government) works together with the local services (service providing) organisations

Q4. How the different local administrations (acute health care, social care, education, housing etc.) work together with each other

Q5. The eligibility and legal criteria for accessing learning disability services nationally and/or locally

Q6. The degree of integration of services for people with profound and multiple learning disabilities (PMLD) with services for people with learning disabilities more generally

Q7. The degree of integration of services for people with challenging behaviours with services for people with learning disabilities more generally

Q8. The various types of advocacy arrangements for people with learning disabilities operating locally and an identification of those which are the most inclusive

Q9. The complaints or appeals procedures available for service users locally and how well they work

Q10. The various service models for people with learning disabilities being promoted nationally and/or developed locally

Q11. The national and/or local evidence of a relationship between different service models and costs

Q12. The staff training and staff development programmes and priorities within local service (providing) organisations

Q13. National and/or local requirements for specialist or professional qualifications for staff working with people with learning disabilities or in social care

Q14. The extent of development of the social care market nationally and/or locally

Q15. The contractual and/or funding relationship between local administrations and service (providing) organisations

Q16. The arrangements for care standards and inspection (regulation) that exist nationally and locally

Q17. The extent to which cost information is individualised in relation to services received by people with learning disabilities

Q18. The arrangements operating for direct payments (personal budgets) to people with learning disabilities themselves

Q19. The profiles and activities of the voluntary sector (nor for profit) organisations nationally and locally in service providing

Q20. The profiles and activities of families in caring and/or campaigning for people with learning disabilities

Q21. The legal and funding relationships between national government and local administrations and/or service organisations in learning disability

Q22. How national (central) government policy and/or legal frameworks impact upon local administrations (government) and service (providing) organisations in:

1. social care
2. health care
3. learning disability
4. anti-discrimination