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*“A journey of a thousand miles  
begins with the first step.”*

*(Chinese proverb)*

## **Improving the lives of people with learning disabilities**

### **STEPS recommendations – structures, tools and methods to develop person-centred and community-based services**

The European action research programme „STEPS – Structures towards emancipation, participation and solidarity“ has focused on structures, instruments and methods to combat discrimination against people with learning disabilities and develop mainstreaming and community-based services. It aims at encouraging full participation and free access to material, cultural and social resources.

The International STEPS-Network is composed of five local partnerships in London, Barcelona, Lidingö, Rotterdam and Hamburg. Each local partnership includes key persons in the field of services for people with learning disabilities: representatives of the local social service and health authorities; health and other independent sector organisations; service-providing organisations and scientific links.

All local partnerships carried out practical projects, which have had the greatest impact on the international theoretical discussion in STEPS. In this document, experience and good practice from five local projects are summarised in short recommendations for the development of person-centred and community-based services.

In our opinion we should start acting before we have all the theoretical answers – Correspondingly this paper does not include a complete theoretical model, but encourages improvements and provides references for good practice.

*“The project is not a European championship about learning disability. This is not a competition. We come from different countries, we have different contacts and different experience and we must respect each other for all our experience. The core of the project is that we put things together and something will grow which will be better than what exists in the single countries. This is important.” Kent Ericsson*



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## SOCIAL DISCRIMINATORY PRACTICE

Social discriminatory practice in western European countries includes:

- Exclusion of people with learning disabilities from decision making processes
- Exclusion from paid work as a basis for personal development and social contacts
- Risk of being excluded from society and the local community
- Economic marginalisation and social exclusion of people with learning disabilities in society and economies
- Barriers in access to mainstream services and education
- Isolation and segregation in institutionalised or congregate service provision
- Hierarchies of power between users and service systems
- Conflict between individual rights and needs and the (economic) interests of service providers
- Protective or paternalistic attitude towards people with disabilities
- Lack of anti-discrimination and equal opportunities training for managers and staff development and competence in these issues
- Fragmented disability policy and fragmented accountability
- Existence of dominant cultural norms concerning age, gender, sexuality and ethnicity, in addition to disability
- Lack of anti-discrimination staff training, development and competence



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## NATIONAL LEGAL AND POLICY FRAMEWORKS

*“Society is based on democratic rights and human values:  
the vision must be to protect these.”*

*(Lars Lööw, Swedish Disability Ombudsman)*

We refer to International and European legislation which has the potential to have a direct impact on equality, combating discrimination and realising human rights for people with learning disabilities. In our opinion the interpretation and the implementation of the legislation at a local and regional level would be the most effective way to improve the lives of people with learning disabilities.

- Universal Declaration of Human Rights
- International Covenant for Civil and Political Rights
- International Covenant on Economic, Social and Cultural Rights
- Convention on the Elimination of All Forms of Discrimination against Women
- Convention on the Rights of the Child
- United Nation’s Standard Rules on Equal Opportunities for People with Disabilities
- Ottawa Charter for Health Promotion
- Charter of Fundamental Rights of the European Union
- European Disability Strategy
- European Employment Equality Directive (2000/78/EC) following the Treaty of Amsterdam



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## CITIZEN AND HUMAN RIGHTS PERSPECTIVE

All human beings are born free and equal in dignity and rights. People with learning disabilities are citizens and members of society and have the same rights as any other man or woman to:

- live a good and ordinary life
- live a meaningful life and have meaningful occupation/employment
- have an individual biography
- establish friendships and relationships and express themselves sexually
- be visible and meaningful in society
- receive appropriate, equitable and fair services
- recognise cultural and ethnic diversity within disability
- recognise and decide about different opportunities
- risk and disappointment

### *Recommendations:*

A shift in culture, an attitude change is necessary:

- ⇒ from the institutional point of view to the user's point of view.
- ⇒ from institutional life to community and economic participation.
- ⇒ The cultural shift needs to be initiated by European and national guidelines and be backed by local initiatives.
- ⇒ Cultural and ethnic diversity within disability has to be recognised.
- ⇒ Division between private and public sphere (work, employment) should be considered. Housing, leisure and work should be recognised as separate spheres of life, which are connected by the individual.
- ⇒ Meaningful occupation means inclusion in work and employment.
- ⇒ Work and employment are main factors of inclusion and should be particularly valued.
- ⇒ Citizenship includes interdependency: It needs to be supported.



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## NATIONAL LEGAL AND POLICY FRAMEWORKS

The importance of national policy framework for directional guidance is clear but flexibility in responding to local or regional needs is also necessary. Policy formulation also needs to attend to rigid national and local funding systems of service provision 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.

To realise de-institutionalisation and person centred services a special policy framework is needed. Such a policy framework must regulate funding systems and determine the level of accountability.

The STEPS partners are aware that rapid and frequent policy change can prove to be destabilising if not well implemented and supported locally and that policy change at national level will not necessarily influence local practice. There is also a risk that policy could become trapped in cycles of deregulation-regulation on the basis of political ideology, rather than focusing more directly on the quality of services provided for people with learning disabilities.

National legislation and national action plans can help to improve the life of people with learning disabilities:

- Anti-Discrimination and Equality Acts for different social fields and groups and grounds
- National Civil Rights
- National Action Plans

### EXAMPLES:

Spain: National Action Plan for Social Inclusion

Sweden: National Plan for Disability Policy

United Kingdom: Disability Discrimination Act 1995 as amended 2003



- National Closure Programmes

**EXAMPLES:**

England: Care in the Community Programme

Sweden: Institutional Closure Programme

- Integrated law for people with disabilities

**EXAMPLES:**

Spain: LISMI – Spanish law for social integration of people with disabilities

Germany: SGB IX: Social Code Book IX, integration and  
rehabilitation of people with disabilities

Netherlands: AWBZ – General Law concerning special health costs

- Organisations and bodies to assist in combating discrimination

**EXAMPLES:**

Sweden: Disability Ombudsman

Spain: Office of Non-Discrimination

Netherlands: Federal Ombudsman

*Recommendations:*

- ⇒ Legislation should enforce the use of clear eligibility criteria, forms of assessment and access routes for services.
- ⇒ Legislation should define clear responsibilities for services and funding, e.g. municipal and regional responsibility.
- ⇒ Legislation should define learning disability and provide minimum expectations for assessment and service receipt.
- ⇒ Legal advocacy should be easy accessible.
- ⇒ Legislation should guarantee the client's right to participate in decision-making committees.



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## ADVOCACY / SELF-ADVOCACY

*"We are trying to break the cycle of telling the person what is good for them."*

*(Patricia Ericsson)*

Advocacy is defined as the process of identifying with and representing a person's view and concerns in order to secure enhanced rights and entitlements undertaken by someone.

(Henderson and Pocin, 2001).

A wide range of approaches in advocacy: legal, professional, collective, citizen and peer advocacy have been identified. In self-advocacy people are encouraged to speak for themselves and demonstrate self-empowerment.

Advocacy is a device, which should ensure the human rights of the user and the power of their voice. It should strengthen the person's position in society. It is a device which reduces the power of authorities or service-providing organisations.

*"Advocacy should ensure legality and equality.*

*It should respect the client's personal integrity."*

*(Michael Langhanky)*

### *Recommendations:*

- ⇒ Advocates and advocacy groups should be independent of the local authority/ administration and the service providers.
- ⇒ Special issues need to be considered for advocacy arrangements for people from black and minority ethnic backgrounds. Differences, fears and previous experience of exclusion have to be acknowledged.
- ⇒ Views of vulnerable adults, for example minority ethnic people with learning disabilities, have to be obtained without fear of recrimination.
- ⇒ Freedom of consenting sexual expression needs to be part of self-advocacy and empowerment.
- ⇒ Advocacy has to reinforce gender equality.
- ⇒ Advocacy and complaint procedures need to be provided at grass roots level and should be linked with the complaint instruments on the organisational level.



## EXAMPLES:

K & C: Self advocacy group People First and Advocacy Alliance; Its my Life group; Citizen Advocacy (CAB) and various provider organisations, e.g. Equal people  
The Netherlands: Federation of parents on the local level and client boards  
Barcelona: Guardianship

## DECISION MAKING / USER INVOLEMENT

*“We don’t want to talk about our life, we want to decide it.” (German User Group)*

*The STEPS network recommends:*

- ⇒ Formalised user involvement in the management of service provider organisations and on a political level should be enforced by law. The involvement should exceed the formal level and have practical impact on the lives of the people.
- ⇒ In local authorities and health and service providing organisations, user involvement is necessary to reduce the power of administrations or service providing organisations and to enhance the power of the user’s voice.
- ⇒ Information and knowledge has to be freely available, in an accessible and timely manner and has to be easily understood. Different forms of communication (e.g. sign language) have to be used. Decision-making takes time!
- ⇒ People need to experience possibilities and alternatives to make informed choices.
- ⇒ Opportunities should exist for people to explore personal budgets.
- ⇒ Protected space for for the communication of the views of black and minority ethnic service users to managers and service providers should be made available.
- ⇒ Relatives and parents must be important stakeholders in the decision-making process. However, as they may prefer institutional care – which can work against the self-determination, human rights and chance for people with learning disabilities to lead ordinary lives in the community – they are not the primary partners.



## EXAMPLES:

K & C: User Forum and Consultation Boards,  
Quality network, Interview group, Yarrow Theatre Group  
Germany: user advisory councils at local level  
in service-providing organisations and sheltered workshops

## NEEDS ASSESSMENT

Needs assessment is a device, which is used to define someone's eligibility for services.

- ⇒ Needs assessment should be carried out by an agency or organisation independent of the service providing organisation and the local authorities.
- ⇒ Needs assessment must reflect and include cultural appropriateness – ethnic, religious, cultural and lifestyle belief systems about learning disabilities, care and management etc.
- ⇒ Needs assessment should be clear about the difference between needs and wants and the necessity for resource-needs matching. It is senseless to assess for a need if one is unable to meet it.

## PERSON-CENTRED PLANNING

*“They listen to us but they don't care what we say.” (Swedish user group)*

Individual service planning and person-centred planning arrangements are powerful tools in supporting positive change and in finding out what is important to a person. They help the person to take control of their life and to speak for him or herself.. Person-Centred Planning is an important device in connection with personal budgets and direct payments.

Person-Centred Planning helps to ensure that diversity and equality are regarded as important aspects of daily life.



*Recommendations:*

- ⇒ Person-Centred Planning needs to be properly embedded in the strategic planning of services at community level.
- ⇒ Person-Centred Planning should be available for everybody. It should be flexible and at the pace of the individual.
- ⇒ Person-Centred Planning should be a long-term process and contribute to durable and reliable arrangements. The biography of the persons should be well documented.
- ⇒ Relatives and friends should be included in the planning process.
- ⇒ Person-Centred Planning should substitute – and not supplement conventional planning structures. Planning structures should be stream-lined.

**EXAMPLES:**

- K & C: Person centred planning
- Lidingö: Seasonal meetings
- Hamburg: Alsterdorfer Advice Agencies
- Das Rauhe Haus: Service Conferences

**SERVICE SYSTEMS / MODELS**

*“We have to close the institution in our mind!” (Kent Ericsson)*

The STEPS partners recommend continuing towards decentralised and community based services even if highly decentralised arrangements appeared to risk the development of inequality at local level.

**EXAMPLES:**

- Lidingö: Local and municipal responsibility
- Rotterdam: Circles of friends

*Recommendations:*

- ⇒ The STEPS network recommends continuing with the shift from institutionalised learning disability services to community-based care and to small and individualised services. De-institutionalisation should be continued.
- ⇒ The placement of children in institutions should be halted.
- ⇒ New institution admissions should to be avoided.
- ⇒ Policy makers (not service providing organisations) should set objectives and frameworks for change and develop plans. The job of providers is to decide en route.
- ⇒ Different organisations may need to be involved in achieving service shifts with new staff without institutional attitudes.
- ⇒ Local inequality in service access and provision, which may result from devolved authority and decentralisation, should be managed and regulated through national standards.
- ⇒ National standards as well as inter-authority co-operation can help to secure regional justice and horizontal target efficiency.
- ⇒ STEPS gives priority to community based services. Local resources and informal needs should be identified, documented and used.
- ⇒ Peer group relationships and family and social networking must be supported and facilitated.
- ⇒ The co-operation of municipalities and health organisations can answer the needs of people with disabilities and correct regional imbalances.
- ⇒ Service systems and decision-making should be transparent, open and accountable to both the community and service users.
- ⇒ Bureaucracy should be avoided.



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## MAINSTREAMING / SPECIALISED SERVICES

The integration of services for people with learning disabilities into mainstream services such as housing, education, health or leisure is recommended.

### *Recommendations:*

- ⇒ Multi-disciplinary/joint-community teams appear to be a key device in supporting mainstreaming and integration. Specialist workers and appropriate resources could also be integrated into general services.
- ⇒ Specialist learning disability training should be offered to mainstream service providers.
- ⇒ Personal assistance, e.g. health assistance, should be provided.
- ⇒ Specialised and general services can be offered in the same building.
- ⇒ Specialised services for special needs are required – disability must be recognised (not ignored).

### **EXAMPLES:**

Barcelona: Community centres

Lidingö: General local-government services for people with learning disabilities

Sweden: Day Services for Children, Education

K & C: Joint community teams

Rotterdam: Down's Syndrome teams in ordinary hospitals

## MIXED ECONOMY / SOCIAL CARE MARKET

In the STEPS network, the need to diversify the supply of services is generally accepted. Market systems generate efficiency but create distortions in provision.

- ⇒ A mixed economy or a quasi-market approach appears to offer more potential for effecting change in the balance and pattern of services.
- ⇒ A mix of state /local government and voluntary and non-profit organisations enhances the service user's choice and administration when contracting or arranging services.
- ⇒ Market systems require more elaborate monitoring and regulation.
- ⇒ Market management is needed to meet more complex needs.
- ⇒ Users should be supported when moving into commercial models and social firms.



## EXAMPLES:

Rotterdam: Supported employment in the profit-sector and social first and reintegration in the first and second labour market

## SERVICE PLANNING

### *Recommendations:*

- ⇒ Service systems and organisations need to be user-centred. Services should be consistent, logical and accessible and should be organised according to the people's needs, wishes and desires.
- ⇒ The service users need to be involved in service planning at the macro-level e.g. at partnership board level and in quality networks. Adequate support should be provided.
- ⇒ Lead responsibilities for inter-agency planning in learning disabilities and community care are required.
- ⇒ More inclusive 'stakeholder' or 'constituency' planning systems should be established which break down monopolies of influence. The service systems need to be planned and co-ordinated with other stakeholders.
- ⇒ Permanent flexible services as well as risk management for daily life requirements are necessary.
- ⇒ Service systems have to be planned at local level and be focussed on mainstreaming and co-operative structures.
- ⇒ Integrated care management within the context of multi-disciplinary /specialist teamwork are recommended.
- ⇒ An increasing need for inter-agency and inter-professional working must be recognised.
- ⇒ Bridge builder's capacities should be supported.

## EXAMPLES:

K & C: Quality Network, Partnership Board, Its my life group



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## FUNDING/COST MANAGEMENT ARRANGEMENTS

An appropriate level of funds for people with learning disabilities in all European Countries should be made available. Furthermore, the STEPS partners would like to encourage a rethink of cost management systems towards new person-centred funding systems.

### *Recommendations:*

- ⇒ In the context of clear responsibility and accountability, priority should be given to unambiguous organisational and budgetary arrangements, e.g. a single pooled budget instead of different fragmented financial sources. STEPS recommends the pooling of separate funding streams into a single budget.
- ⇒ Guidelines on the financing of social services should be made more transparent.
- ⇒ Alternative funding sources should be explored at strategic levels.
- ⇒ The budget should be ring-fenced for learning disabilities.
- ⇒ Aggregated information on service costs and needs are necessary for strategic commissioning.
- ⇒ Effective IT management information systems on costs and needs are required in order to link macro and micro planning systems.
- ⇒ The process of targeting criteria locally and nationally, while matching resources to needs and ensuring equitable provision should be developed.

### **EXAMPLES:**

Lidingö: Financing of services

London: Pooled budget

In the STEPS project, direct payments and individual budgets are seen as a tool to realise the shift from institutionalised disability services to community based care and from mass provision to small and individualised services. It is a vehicle towards promoting user choice and power.



*Recommendations:*

- ⇒ Funding should be related to the person, not the system.
- ⇒ Direct payments and individual budget should be promoted.
- ⇒ Direct payments need checks and balances to protect the user and accountability for public funds

**EXAMPLES:**

Peter Peeters: Personal budget

K & C: Statutory footing for direct payments in England

<b>QUALITY ASSURANCE</b>
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STEPS recommends developing public control, service standards and user control as well as in-house tools.

*Recommendations:*

- ⇒ Quality inspections should be an integral part of funding and service planning arrangements as well as purchasing and commissioning more widely.
- ⇒ Technical quality should be guaranteed by the service-providing organisation. Functional quality should be evaluated by the users. Users should be integrated as 'quality inspectors'.
- ⇒ External scrutiny and control need to be developed.
- ⇒ National standards and central monitoring and inspection agencies could be used to ensure that minimum standards are met.

**EXAMPLES:**

K & C: Quality Network and Placement Monitoring Team  
for out of authority and internal placements



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## SERVICE PROVIDING ORGANISATIONS

With respect to the structure of service providing organisations, the STEPS network recommends:

- ⇒ Not for profit organisations – often church, family or voluntary organisations – are necessary to develop community-based and user-oriented services. Community based structures could also be provided by public services in co-operation with not for profit or profit organisations.  
In this context some organisations prioritise market orientation combined with a solid economic base and reliable structures.
- ⇒ Service-providing organisations with a monopoly should be decommissioned or split into smaller not for profit organisations following needs analysis.
- ⇒ National guidelines on provider markets and performance are required.
- ⇒ Profit should be invested to improve the services as a mechanism for change within the organisation.
- ⇒ Specialist providers should be encouraged to meet needs of black and minority groups e.g. services for Asian women.
- ⇒ Powerful and large service-providing organisations have the possibility of and have the responsibility for investing in innovation: both internally and externally.
- ⇒ Service-providing organisations have to include internal “brick walls” to reinforce the user’s legal position and power.
- ⇒ Service-providing organisations should be responsible for providing services in a local area.
- ⇒ The co-operation between service-providing organisations is necessary.

### EXAMPLES:

Hamburg: Development of Alsterdorf, Das Rauhe Haus

Rotterdam: PameijerKeerkring



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## ORGANISATION AND LEADERSHIP

The attitude shift in social and health services for people with learning disabilities should be reflected in changing leadership principles.

### *Recommendations:*

- ⇒ The STEPS network recommends consultative rather than authoritative, non-hierarchical, inclusive leadership and organisations.
- ⇒ The management should be supportive and facilitative.
- ⇒ To empower the staff, there should be clear guidelines in place.
- ⇒ Responsibility should be clearly defined at every hierarchical level.
- ⇒ Clear authority and accountability are to be developed at local level.
- ⇒ Single management accountability for community services should be prioritised. Split management and accountability causes fractures in services.

## INTEGRATION IN WORK

Paid work is arguably the most important tool for integration. Accordingly, it has a high priority in international and national policy frameworks and legislation.

The STEPS partners underline the objectives of integrating people with learning disabilities into the first and second labour markets and of increasing the number of jobs in the community. In contrast, sheltered workshops and sheltered work, which excludes disabled people from the regular labour market are to be avoided.

### *Recommendations:*

- ⇒ Work should be a fundamental right.
- ⇒ Paid work and employment possibilities in the community should be offered to everybody. Supported employment in 'ordinary' jobs should be the first priority.
- ⇒ Individual work and employment assistance could offer support for people with learning disabilities.

- ⇒ Politicians and policy makers should remove financial disadvantages for people with learning disabilities who seek paid employment. As we live in society determined by economical factors, people with disabilities should earn an appropriate salary.
- ⇒ Appropriate incentives for the first labour market should be provided to employ those with disabilities.
- ⇒ In service and future planning, work and education should play roles as significant as housing and care.

#### **EXAMPLES:**

Rotterdam: Integration in OMIJ

Lidingö: meaningful occupation in the Ö-Gruppen

Hamburg: Small working projects

### **EDUCATION AND FURTHER EDUCATION**

The user group in STEPS emphasise the importance of education and further education. They aim to develop their skills and to have access to the first labour market.

#### *STEPS recommends:*

- ⇒ Supported education in mainstream schools.
- ⇒ People with learning disabilities should have life-long learning opportunities and access to further education in mainstream establishments.
- ⇒ People with learning disabilities should be included as peer trainers and reviewers.
- ⇒ Alternative and non-traditional forms of communication in education should be used.
- ⇒ Training in social competence, independent living skills, communication skills, participation, finance, improving self-advocacy and autonomy.
- ⇒ Training in skills for employment.
- ⇒ Training and higher educational qualifications for people with learning disabilities, which are accepted in the regular labour market.
- ⇒ Training should be also offered to the relatives.



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## WORKFORCE DEVELOPMENT

Community work and bridge-building are some of the most important tasks to be undertaken by professionals. The attitude of the workforce is an important factor in realising community-based services. In this context, workforce competence should be adequately valued.

Professionals with an institutional background should be qualified to run community-based services.

### *Recommendations:*

- ⇒ Competence in social and community matters is necessary.
- ⇒ Competence concerning ethnic diversity to meet the various cultural needs of users and their families.
- ⇒ Communication skills are necessary.
- ⇒ The STEPS partners give priority to the fundamental development of practice competence, the exchange of experience and innovation and the promotion of trans-disciplinary work in a multi-agency context.
- ⇒ National standards and targets for staff qualification for workforce development in social care would be useful. To develop management and practice competency, additional training and development programmes are required.

### EXAMPLES:

Tizard Centre's Certificate,  
Diploma and BA in Health and Social Care Practice