

Achieving Quality

Consumer involvement
in quality evaluation of services



Inclusion Europe

Report

Inclusion Europe and its 47 national, regional and local member associations in these 33 countries are fighting for the rights of people with intellectual disability and their families:

- Austria
- Belgium
- Bulgaria
- Croatia
- Czech Republic
- Denmark
- England
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Iceland
- Ireland
- Israel
- Italy
- Lithuania
- Luxembourg
- Macedonia
- Moldova
- Netherlands
- Norway
- Poland
- Portugal
- Romania
- Russia
- Scotland
- Slovakia
- Slovenia
- Spain
- Sweden
- Switzerland

This publication is one of the products developed in the project “People with Intellectual Disability as Consumers of Support Services” supported by the European Commission. Other products can be found at the website of the project under <http://www.inclusion-europe.org/consumers>.

The project partners contributing to this publication were:

Lebenshilfe Vienna
Schönbrunnerstrasse 179
1120 Vienna
Austria
Tel.: (43) 1-812.26.35

Federatie van Ouderverenigingen
P.O. Box 85276
3508 AG Utrecht
Netherlands
Tel.: (31) 30-23.63.767

ANAHM
Av. Albert Giraud 24
1030 Bruxelles
Belgium
Tel.: (32) 2-219.88.00

ISBN 2-930078-86-3

© Inclusion Europe, Brussels 2003

Art on cover page: “Bird of Paradise II” by Herta Feichtenhofer
Nahtloskunst Kindberg, Austria

This publication presents the views of Inclusion Europe and does not necessarily reflect the position or opinion of the European Commission. The European Commission and Inclusion Europe are not liable for any use that may be made of the information contained in this publication.

Consumer involvement in quality evaluation of services

Introduction

This brochure is one of the results of the European project “People with intellectual disability as consumers of support services”. This project was coordinated by Inclusion Europe and financed by the European Commission. Its main objective was to take up recent developments in European consumer policy including its implications for the role of the users of support services.

While other materials produced within this project are addressed to service users (e.g. the booklet “I know what I want! I buy what I want!”) or to supporters, parents and frontline staff (Trainers Manual), this paper is mainly conceived as an input for all persons responsible for the outcome quality of support services. This booklet should give an impulse to think about what the new role of users as consumers of support services could mean for the design of quality evaluation systems in the social field.

What this brochure wants to achieve

The aim of this paper is to raise awareness of the fact that changes in the approach towards the “clients” or “consumers” of services for people with intellectual disability do have an important impact on the way the quality evaluation systems of these services should be designed and organised.

What this brochure definitely does not want to be

This brochure does not claim to offer an overview of the broad field of quality management models for social services. It claims neither scientific validity nor comprehensiveness.

A new approach towards quality

This brochure wants to introduce a philosophy about quality evaluation where the users and their advocates – who can be parents, case-managers or other support persons – play the central roles. This focus on the users will be placed in the context of a new view on people with intellectual disability as users of support services. They are no longer forced into a passive role of dependent recipients of help. They are viewed as potentially strong consumers who actively evaluate and influence the quality of their support – of which they expect that it meets their needs and wishes.

Advocates play a double role in this. On the one hand they can provide assistance where necessary to support people with intellectual disability in the role of active consumers. It has to be stated on the other hand that advocates have always had - and will have in the future - a role on their own. From the perspective of an organisation of people with intellectual disability and their parents, we want to stress the fundamental role that advocates - be it family members, guardians or other advocates - have played in the enhancement of the quality of support services.

Acknowledgements

Several people and organisations have contributed to this brochure. We would particularly like to thank Klaus Candussi (ATempo, Austria), Prof. Bea Maes (University of Leuven, Belgium) and the project partners Lebenshilfe Vienna, Federatie van Ouderverenigingen (Netherlands) and ANAHM (Belgium) for their contributions.

Involvement of customers creates better quality

Quality management in social services

For the last decade, models of Total Quality Management have finally percolated the field of social services. User organisations and governmental decrees have forced service providers to make use of quality management instruments to assure and enhance the quality of their services.

Approaches to quality evaluation should become independent

Due to the different reasons for the implementation of quality management, service providers have applied different kinds of instruments. And owing to restricted financial resources, the focus on cost efficiency and quality of management processes was predominating.

Governments, moreover, often have the tendency to reduce quality management to a question of minimum standards, mostly focussed on issues of structural quality. Experts in special education on the other hand established quality instruments to prove the effectiveness of their educational programs.

Therefore it would be desirable to establish systems of quality evaluation that are independent from and not influenced by service providers or governments.

Why quality management need the service users

Leaving all the benefits of the above-mentioned quality measures aside, there are mainly two reasons why systems of quality management have to be complemented by instruments based on the perspective of service users.

- The **right to participation** for people with intellectual disability has not only explicitly been enshrined in international treaties and conventions, it can also be deduced from their role as consumers. According to this role they have the power to influence the services which are paid to organise their personal support, the right to choose and to complain.
- The **right to self-determination** implies that the role of people with intellectual disability is changing from the passive role of dependent recipients of care towards one of active consumers who determine themselves the goals they want to pursue and the changes they want to realise in their lives.

Establishing instruments of quality management which refer to the perspective of service users leads necessarily to changes in the focus of quality evaluations.

The special role of advocates

Most people with intellectual disability have much more abilities for independent decision-making than attributed to them in the past. However, the nature of their disability makes a support by advocates in more complex issues often indispensable. This applies especially for people with severe and profound intellectual disability.

Unlike past and often present practice, the views of advocates should in no way simply substitute the voice of people with intellectual disability. Family members, guardians, peers and other advocates should add their own independent view and concerns and therefore complement rather than replace the views of the person with intellectual disability. Adequate quality management in services for people

with intellectual disability can only take place in cooperation of three different groups of actors: people with intellectual disability, their advocates (their role being consumer protection), and the service providers.

Input orientation versus output orientation

In evaluating the quality of services consumers naturally focus on the outcome quality and are less interested in the questions of structural quality or the quality of processes. Because from the perspective of governments or financial managers proper evaluation instruments are mostly input oriented and they are not suitable for the evaluation of service quality from the perspective of consumers of social services.

Suitable evaluation instruments therefore have to measure quality items of services objectively, or could measure consumer satisfaction.

Quality is evaluated from the client's perspective

Standards and uniformity are not adequate

Quality evaluation from the client's perspective is about their personal experience with their housing, living, working conditions. The focus should be on the achievement of outcomes derived from the person's preferences and lifestyle. Different aspects can be evaluated:

- their satisfaction with certain aspects of their life and the support they are getting
- the value and relative importance people attach to these aspects;
- the degree to which their individual needs, wants and preferences are met;
- the degree to which they can aim for personal objectives;
- the degree to which they have the feeling that change or improvement is possible.

Clients want quality-of-life outcomes

The concept of quality-of-life, however, is very broad and consequently very difficult to evaluate in the context of the quality of support services. It makes little sense to tackle the quality of a service generally. Quality assessment from a consumer perspective takes this perspective into account on all levels of the assessment. What does this mean? Persons with a disability identify for themselves, perhaps with support, what are important and valued outcomes in certain areas of life and determine whether these outcomes are achieved or not. All areas that are relevant to the person concerned must be given a place in the quality evaluation.

A multidimensional approach shaped by the client

Depending on the importance of a certain area of life to a client, this area can be taken into account when evaluating the quality of support and services. The following areas of life that are encompassed by this broad concept of quality-of-life:

- Emotional well-being, covering aspects like security, spirituality, happiness, self-appraisal, sexuality, etc.
- Social relations, covering family relations, friendships, intimacy and affection, good relations with co-residents, etc.
- Community affiliation and inclusion, covering social contacts with people in the local community, being accepted and respected, social participation, etc.
- Material well-being, covering property, money, a secure and comfortable home environment, etc.

-
- Personal development and constructive activities, covering access to educational activities, learning skills, having meaningful work and leisure activities, participating in domestic tasks, etc.
 - Physical health, covering health, food, mobility, access to health care, etc.
 - Self-determination in making choices and decisions, exerting influence on the environment, having a preferred lifestyle, etc.
 - Civic equality and involvement, covering the right to participation, information and education, access to general services and specific care, etc.
 - Protection from violence, abuse, physical and emotional harm and discomfort, neglect, etc.

Regular evaluation is necessary

Because needs and preferences change in the course of life, quality of life-outcomes are not fixed and definite. Therefore, quality evaluation from the client's perspective must not be a once-only event, but something that takes place regularly.

Quality of life is determined by the support

The quality of life experienced by disabled people is determined to a certain degree by the kind of their support services. That is why researchers – on the basis of focus groups comprising persons with disabilities, advocates, professionals and decision makers – have defined some support processes that contribute to a significant degree to positive quality-of-life outcomes:

Person-centeredness: each person with a disability is acknowledged as an individual with unique potentialities and needs. One of the most important quality criteria therefore is that support should be individualised and person-centred.

Full participation in society: people with a disability must have inclusive, community-based educational, employment and living options. Support is directed at participation in community-based activities and at interactions involving people with and without disabilities.

Dignity and respect: support must be given in respect and esteem for the integrity and the personal life style of each person. They should also be protected against all kinds of violence, abuse and neglect.

Choice and control: people with a disability must be given every opportunity to make their own choices and to exercise decision-making concerning their living conditions, work, leisure time, relations etc. They are encouraged to act as the primary agent in their life and to achieve personal goals.

Relations: people with a disability should feel a bond with and commitment to family, friends/acquaintances. Support must be directed at extending and strengthening this relational network.

Independence and development: support is directed at raising clients' confidence in their own competencies. At the same time they are stimulated to develop skills and to carry out tasks and activities as independently as possible.

Engagement in varied and stimulating work and leisure time activities: persons with a disability must be supported to participate in activities according to their interests and choices. In so doing, they become open to a large range of life experiences.

It needs to be stressed once again that 'standards' like this only make sense if they are used as the link between the service conditions and efforts, and the aspects of quality of life – in terms of outcome – expected by a client.

How consumer involvement can work

Consumers are the best source of information

Who should know better about the quality of services for people with disabilities than the members of this group themselves? The fact that many people with intellectual disability have limited (verbal) abilities to communicate should lead to extensive attempts to use alternative means of communication rather than to carry out quality evaluation without their involvement.

Advocates, like family members, guardians or peers, are an important and necessary complement, but should never substitute the perspective of the people with intellectual disability.

Strategies of consumer involvement in quality management

There are several possibilities to integrate the contributions of service users and their advocates into the work process of services to enhance their quality:

- strategies of person-centred planning allow people to think about their life, to make choices as to the future and to undertake actions to realise the objectives they have assumed.
- case managers acting on behalf of their clients are urged to base their negotiations with service providers on a clearing process in which clients and their advocates can indicate to which degree the support package is adequately tailored to their abilities, needs and aspirations.
- by means of personal interviews, visits, job traineeships or model houses persons with intellectual disability can check out how, where, with whom and with what support they want to live, work or spend their leisure time.
- interests can be assessed with activity lists and personal lifestyle preferences by questionnaires, interviews or observation.
- participation in the way support is given or the service policy can also take the form of consumer board meetings.

Strategies of consumer involvement in quality evaluation

Strategies to evaluate the outcome quality from the perspective of the consumers could focus on items of consumer satisfaction or on items indicating an objective level of service qualities.

How to evaluate consumer satisfaction

The individual or collective satisfaction of service users can be investigated by

- internal or external evaluations using questionnaires or interviews. In case of missing communication skills, satisfaction can be discovered through participatory observations.
- using accessible complaint procedures to stimulate customers to give feedback.

Consumer satisfaction is not enough

Two fundamental problems are to be taken into account when evaluating consumer satisfaction. It is often seen that people with intellectual disability - maybe as a result of their special socialisation - show a tendency to give "socially desired

answers”. On the other hand, personal satisfaction mainly is result of a comparison of a present with a past situation. Therefore, the same service quality might lead to different judgements according to different experiences of consumers. Many people with intellectual disability also face the problem that they have only a very limited range of experience with different possibilities due to institutionalisation or poor services in their history.

Therefore, it is useful to involve also family members, guardians or peers as advocates in the evaluation of consumer satisfaction. They can provide the necessary corrective between the limited life experience of the user and the interests of the service provider.

Objective measurements of service quality

A valid judgement on the outcome quality of services has to be based on an evaluation system working with objective criteria. This valid basis is also needed to provide the opportunity to benchmark the results of different services.

How to involve consumers in the evaluation?

There are different ways to involve service users in evaluation measures:

- the experience of people with intellectual disability as service users can be used in formulating the questionnaires or interview guidelines for quality audits of services.
- people with intellectual disability can be trained to do interviews with their peers in an external audit. This brings the advantage that the small social distance between the interviewer and the respondents minimises the tendency to “socially desired answers” and this way leads towards more valid results.
- wheelchair users for example can carry out standardised accessibility tests to evaluate whether a service facility is accessible not only on the architectural plan but also in reality.

What conditions are necessary for consumer involvement?

To successfully involve people with intellectual disability in quality evaluation some necessary conditions should be considered:

- Open, general or abstract questions should be avoided. Questions should be linked to the real life-experience of the service users.
- Respondents should be motivated by explaining the objective of the inquiry and the goals of the quality measures.
- A positive interview situation should be created; e.g. the respondent should decide on the place and time of the interview.
- The pace has to be adjusted to the needs of the respondents.
- Questions and possible answers should be easy to understand and accessible to persons with low communications skills. This can be supported by using easy-to-read texts and by using visual presentations like pictures, graphics and symbols.

Quality depends on the kind of service and the style of support

Research on the quality of life of service users demonstrates that structural items of services (e.g. small size, community location, typical housing design) may be a necessary condition for the promotion of good quality, but are not sufficient.

Staff attitudes towards the service users, the working methods and the organisational procedures which shape what staff does and how support is given are also crucial factors which determine the level of outcome quality for service users. For this reason, quality evaluations should deal with all these dimensions.

Who needs to get involved?

People with a disability are the main actors

People with intellectual disability have the right to accessible information to know and understand what support is available. This accessible information together with the sharing of good practice should make it possible for them to make 'informed' choices in choosing and using services.

They should be sensitised and trained regarding their role in the evaluation of the quality of services. They must be informed about the possible strategies to give their opinion on quality of services and support, and to realise quality of life outcomes.

Advocates, like family members, guardians or peers, can contribute important complementary opinions and views. This is especially important for people with severe or profound intellectual disability.

Conflicting interests?

Staff members or parents have often taken the role of advocates for their clients or their children. It has often been overseen that the interests of clients or children do not necessarily coincide with the interests of their advocates and that the role of advocates might be in conflict with other interests they might have.

As we have stated before, advocates play a double role. They should be involved in the process of quality assurance as "secondary consumers" in an own, defined role within the evaluation process. They can also – if necessary – support people with intellectual disability in expressing their wishes and needs.

However, it is very important that quality evaluation systems which involve advocates supporting users or acting on behalf of users have to assure that these advocates can fulfil their role without being in a conflict of interests. When this condition is fulfilled, the two major actors in quality evaluation will contribute to the enhancement of the quality of support services.

Service providers should know what they aim for

The objectives, values and mission statements that are the basis for the support provided by a service should be clarified and put forward in easy-to-read format. They should all be transformed into well-defined outcome targets.

The person in the centre of the strategies and work processes of service providers

People with a disability and their advocates should be fully involved in planning and evaluating the life conditions, the support and services users of a service receive. This is a collaborative and recurring process. Lifestyles and necessary support are based on personal dreams, interests, preferences, strengths and capacities. Users must have the opportunity to make meaningful choices and informed decisions. Their opportunities and experiences will then be maximised. They can regularly verify to what degree they are satisfied with the support and the quality-of-life outcomes they have.

No quality without interaction and communication

Because the desired quality-of-life outcomes may vary from client to client and may change over time, the service provider must pay continuous attention to client needs and wishes. An open and continuous dialogue where expectations and ex-

periences may be discussed is essential. The relationship between a client and a care professional is typified as full partnership in which they look for a perspective or objective they share. The contribution and perspective of persons with a disability and their families or other advocates is taken seriously and is respected.

The customer is king

The right to be listened to is one of the basic consumer rights. Consequently, the service provider has the 'duty' to show some organisational flexibility. It makes no sense to organise quality evaluation from the client perspective if the managers are not committed to take the clients' opinion into account. An organisation must be flexible and open to creative solutions and innovative thinking.

A core role for policy-makers

Policy makers must take the group of people with an intellectual disability seriously. People with a disability and their advocates should have a stronger influence at *political level*. They want to put in their opinions when it comes to policies to tackle social factors that negatively affect the quality of their lives. Individuals with a disability must be able to participate in a large scale of democratic decision-making processes that directly affect their life and well-being. These statements fit into our general demand towards policy-makers to empower disabled consumers.

Policy-makers also have a responsibility regarding the providers of support services. From the position of funders, they can "force" service providers to slowly increase their quality and involve users and their advocates in this process.

Improving the lives of people with a disability requires national and European commitment to the *values and principles* of person-centred support, full participation in society, dignity and respect, choice and control, relations, independency and development and engagement in activities. These principles should govern all service delivery and support.

Literature

- Ager, A.K. (1998). The BILD Life Experience Checklist. Worcestershire: BILD Publications
- Benjamin, M., Capie, A., & Nossin, M. (1997). Evaluating community services for people with a disability. Wellington: Standards and monitoring services.
- Butterworth, J., Steere, D.E., & Whitney-Thomas, J. (1997). Using person-centered planning to address personal quality of life. In R. Schalock (Ed.), *Quality of life. Vol.II: Applications to persons with disabilities* (pp.5-24). Washington: American Association on Mental Retardation.
- Capie, A., & Ahrens, M. (1996). A strategy for training and involving consumers with an intellectual disability in the evaluation of their community services. *British Journal of Developmental Disabilities*, 42, 36.
- Felce D., & Perry, J. (1996). Exploring current conceptions of quality of life: A model for people with and without disabilities. In R. Renwick, I. Brown & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation. Conceptual approaches, issues and applications* (pp. 51-62). London: Sage publications.
- Finlay, W.M.L., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13, 319-335.

-
- Gardner, J., Carran, D.T., & Nudler, S. (2001). Measuring quality of life and quality of services through personal outcome measures : implications for public policy. In: L.M. Glidden (Ed.), *International Review of Research in Mental Retardation, Vol.24* (75-100). San Diego: Academic Press.
- Hamel, T.; Windisch, M.: QUOFHI - Qualitätssicherung Offener Hilfen für Menschen mit geistiger Behinderung. Bundesvereinigung Lebenshilfe. Marburg.
- Hensel, Ute (2001): QuAnTa - Qualitätssicherung der Angebote in der Tagesförderung für erwachsene Menschen mit geistiger Behinderung. Bundesvereinigung Lebenshilfe (Ed.). Marburg.
- Inclusion International (1993): Quality Evaluation Guidelines as a means of renewal and revitalisation of services by voluntary associations. Brussels.
- Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D., & Pagler, J. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research, 43*, 164-178.
- Lebenshilfe Wien (1996): Arbeitsmappe zur individuellen Entwicklungsplanung.
- Maes, B., Geeraert, L., Van den Bruel, B. (2000). Developing a model for quality evaluation in residential care for people with intellectual disabilities. *Journal of Intellectual Disability Research, 44*, 544-552.
- Matikka, L.M., & Vesala, H.T. (1997). Acquiescence in quality of life interviews with adults who have mental retardation. *Mental Retardation, 35*, 75-82.
- McVilly, K.R., Burton-Smith, R.M., & Davidson, J.A. (2000). Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual and Developmental Disabilities, 25*, 19-40.
- O'Brien, J., & O'Brien, C.L. (2000). *The origins of person centered planning – A community of practice perspectives*. Georgia: Responsive Systems Associates.
- Schwarte, Norbert; Oberste-Ufer, Ralf (2001): LEWO II - Lebensqualität in Wohnstätten für erwachsene Menschen mit geistiger Behinderung. Bundesvereinigung Lebenshilfe (Ed.). Marburg.
- Stancliffe, R.J. (2000). Proxy respondents and quality of life. *Evaluation and Program Planning, 23*, 89-93.
- Stancliffe, R.J., & Keane, S. (2000). Outcomes and costs of community living: a matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability, 25*, 281-305.
- The Quality Network: *Our Lives*. (1998). Oxford: British Institute of Learning Disabilities and National Development Team
- Van der Zwan, A.A., Spijker, H. & Van Borssum Waalkes, J.B. (1994). *Denken over kwaliteit. Een introductie*. Boskoop: Macula.
- Van der Zwan, A.A., Spijker, H. & Van Borssum Waalkes, J.B. (1994). *Behartigen van belangen. Kwaliteitstoetsing door ouders*. Boskoop: Macula.
- Wehmeyer, M.L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*, 371-383.
- Wheeler, J.J. (1996). The use of interactive focus groups to aid in the identification of perceived service and support delivery needs of persons with developmental disabilities and their families. *Education and Training in Mental Retardation and Developmental Disabilities, 31*, 294-303.
-

Inclusion Europe

The European Association of Societies of Persons with Intellectual Disability and their Families

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disability and their families. Our members are national organisations from 33 countries in Europe.

People with intellectual disability are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours.

People with intellectual disability have many gifts and abilities. They also have special needs. They need a choice of services to support their needs.

Inclusion Europe focuses on three main policy areas:

- Human Rights for people with intellectual disability
- Inclusion in society
- Non-discrimination

Inclusion Europe co-ordinates activities in many European countries, including projects, conferences, working groups and exchange meetings. It responds to European political proposals and provides information about the needs of people with intellectual disability. Inclusion Europe advises the European Commission and members of the European Parliament on disability issues.

“Achieving Quality” is a publication developed in the framework of the European project “People with Intellectual Disability as Consumers of Support Services”. The project produced as well a brochure in easy-to-read “I know what I want! I buy what I want!” and training material to help professionals, advocates and family members to address the issue of the rights of people with intellectual disability as consumers of services. The brochure and the training material are available in most of the European Union languages. You can download them on the website of Inclusion Europe.

This publication was made possible thanks to the contribution of:



Lebenshilfe Vienna



Federatie van Ouderverenigingen



ANAHM



Supported by the European Commission



Inclusion Europe

Galeries de la Toison d'Or - 29 Chaussée d'Ixelles #393/32 - B-1050 Brussels

Tel. : +32-2-502 28 15 - Fax : +32-2-502 80 10

secretariat@inclusion-europe.org - www.inclusion-europe.org

EN