

User Councils in Disability Services

Recommendations for good practice



Inclusion Europe

Contents

Introduction.....	2
Creating user-led services.....	2
General Tasks for Service Providers.....	3
Setting up independent User Councils in all services.....	3
Democratic elections of the members of User Councils.....	3
Specification of the roles and responsibilities of a User Council.....	4
Keeping User Councils informed.....	5
Employ people with intellectual disabilities in the service staff.....	5
The Structure of User Councils.....	6
Defining the framework for work and responsibilities.....	6
Representing the rights and interests of all users.....	7
The Tasks of User Councils.....	7
Being involved in important decisions.....	7
Ensuring User Involvement in complaints procedures.....	8
Involvement in staff recruitment.....	8
Involvement in staff training and appraisal.....	9
User involvement in the evaluation of service quality.....	10
Support in assessment procedures and personal future planning.....	10
Necessary Support for User Councils.....	11
Ensuring independent support.....	11
Training: a corner stone for the work of User Councils.....	11
Being involved in the independent movement of self-advocates.....	12
Resource list.....	12

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Foreword

People with intellectual disabilities are full citizens of their countries. Depending on the level of their disabilities, they are able to lead a normal life without support in many areas, to take own decisions, or to solve problems by themselves. In other areas they are able to organise their own informal support networks of friends, colleagues or neighbours. In some areas of life they need professional support in the form of reliable support services that help to take difficult decisions or help to solve complex problems.

Services are provided for people! This simple truth is the starting point for the work of Inclusion Europe to improve the quality of services for people with intellectual disabilities and their families. We also believe that the users of mainstream or special services should have a decisive influence in the way how these services are provided. “Nothing about us, without us!” describes our policies also in this area.

The most effective way of ensuring user control of support services are personal budgets or direct payment programs that enable the user to purchase exactly that kind of support that an individual user needs. These support services are often delivered in the mainstream of society and often do not require specialised congregated settings where a larger number of people with intellectual disabilities are supported in one location. However, most people with intellectual disabilities in Europe still get their support in the framework of specialised services in education and training, in employment and in living facilities.

This publication therefore focuses on how the needs and interests of users can be most effectively represented in specialised services that cater for people with intellectual disabilities in a congregated setting. It is most important that also in these circumstances users gain more control over the services that are provided for their benefit.

Inclusion Europe therefore calls upon all providers of services for people with intellectual disabilities to ensure a democratic and independent representation of users in the management of their services and an effective control of users of the key aspects of service provision. The existence of such independent representation and control is an indispensable indicator of the service quality provided.

An effective way to ensure democratic representation and control by users is an elected body of user representatives in each service, that is supported independently from the service providers’ interests. This body is called in the following text a “User Council”. Inclusion Europe wants to provide in this publication some examples of good practices from several European countries that can support the establishment and running of such User Councils.

This publication is addressed to service providers or supporters of User Councils to provide ideas and background that may help with establishing an effective user representation. We provide also a number of references of resource material in easy-to-understand language that may be used directly by User Councils, mainly in English language. However, Inclusion Europe has compiled a large collection of easy-to-read material in all languages of the European Union. Please contact our Secretariat to know about available resources in your language.

Ingrid Körner
President of Inclusion Europe

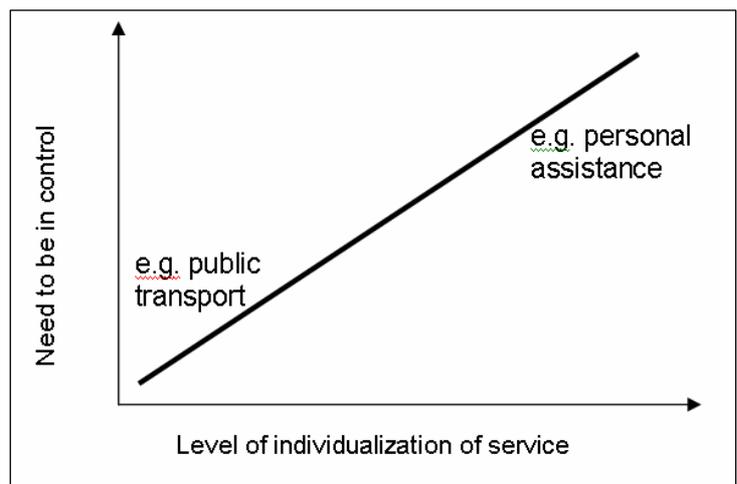
Introduction

Creating user-led services

Inclusion Europe's main objective is to help people with intellectual disabilities to gain more control over their own lives. In many countries, they still spend significant parts of their lives in or using special services. Therefore, it is very important for people with intellectual disabilities to gain more influence and control in the way how these services are provided.

In autumn 2007, Inclusion Europe organised a seminar on this topic with representatives from more than 15 European countries. The participants identified many different types of specialised support services: some are focusing on individual support, like personal assistance; some services are designed for a specific group of people, like sheltered workshops or living facilities; and some services are public and available for everybody.

The more individualised support services are, the more important it is for their users to be in control. For general services, like public transport, the level of individual control is normally rather low and at best realised through elections or general consumer's organisations. If we look at very individualised personal support services, there is a very high need to be in control. Indeed, nobody would think about employing personal assistants without interviewing them personally or without evaluating their work. A person needing a service at this level should be in total control of its implementation.



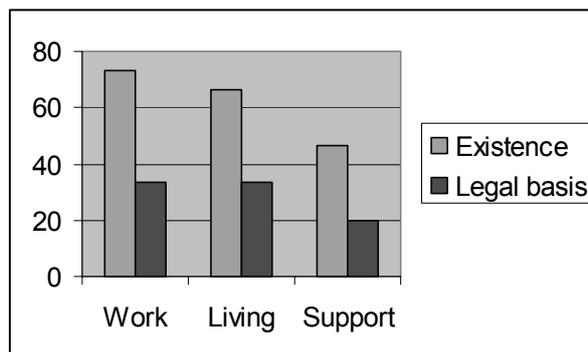
There are different ways of organising the control over disability support services by their users. While individualised personal support services should be absolutely tailored to the needs of each individual, disability services that are delivered to a group of people in a congregated setting require some form of democratic and independent group representation of the users. In this paper, we will call this representation a "User Council".

One of the most important questions for such a User Council is the decision in which of the key aspects of service delivery it should be involved. On the following pages, Inclusion Europe has identified some of the main areas of functioning and decision-making of a User Council that democratically represents the needs and wishes of service users with intellectual disabilities. We have identified good practices supporting their practical implementation and independence from the service provider's interests in order to show how User Councils can work for the benefit of people with intellectual disabilities.

General Tasks for Service Providers

Setting up independent User Councils in all services

Research of Inclusion Europe has highlighted the fact that the existence of User Councils depends very much on the type of services provided. While 73% of all employment services in the responding countries (i.e. mainly sheltered workshops) seem to have some kind of organised user representation, less than 50% of support services do. It is striking, however, that in most responding countries there is no legal basis or obligation to create User Councils in any service.



Many service providers seem to accept it as good practice to establish User Councils in their services. The lack of a legal obligation, however, leads to large regional differences in the responding countries, depending on the attitude of the service provider. Often, these User Councils also lack independence from the interests of a provider, thus not really being able to represent the user's interests. But also in countries and service areas where a legal obligation exists, some User Councils are installed only because of the legal requirement without a real commitment of the service providers to their work.

Good Practice in Germany

There is a law in Germany describing the rights of persons working in a sheltered workshop. The users are entitled to form a Consultative Council. The law includes a very detailed list of activities and decisions where this Consultative Council can claim to be consulted and actively involved in the decision-making process. This includes, for instance, the contents of employment contracts, payment during holidays and/or in case of illness etc. If the workshop does not accept the proposals and claims of the Council, the case may be transferred to a neutral expert unanimously nominated by the service provider and the Consultative Council.

This good practice is limited by the fact that while the expert may propose a solution, the final decision is still made by the service provider of the sheltered workshop. Also there is the question about how independent these User Councils are from the provider interests.

Good Practice in Belgium

The public agency taking care of all services for people with disabilities in the French-speaking area of Belgium is called AWIPH. They have produced about 15 "fact-sheets" on the different services they offer, and they specifically demand that a User Council functions in each service. They explain who should be members of this Council and what its mission should be.

These missions are – unfortunately – kept at a level of suggestions without mentioning the possibility for User Councils to interfere in the decision process. *"The council is constituted of representatives of the users and, if needed, of their legal representatives. Its mission is to formulate suggestions in regards to the quality of life and to the practical organisation of the service provided to the users."* The agents inspecting the services have to check if a User Council is set up in each organisation they visit, but the low level of specifications regarding the missions of the User Councils makes it a hard task for them to evaluate the quality of functioning of such a representative group. Furthermore, service providers are not required to ensure independent support for these User Councils.

Democratic elections of the members of User Councils

As one precondition to ensure independence from the service provider's interests, it is important that all users of a service have the possibility to elect a User Council or to be elected as user representative. To ensure a democratic process, the development of clear election procedures is a key element. They should state at least

- when and for which periods elections should take place;
- that only service users, but no staff members, can vote or be elected;

- that the elections are confidential;
- that no service user should suffer from any negative consequences for standing for election;
- how many members of the User Council should be elected;
- that the voting lists should include pictures of the candidates;
- which independent persons will be asked to count the votes;
- how the election process will be supported by the service provider.

It is important that the service provider informs all service users early enough and in an accessible format about the planned elections. Service providers should not exert any undue influence on the nomination of candidates and the election process itself. Staff costs and all other costs related to the election of a User Council should be financed by the service provider.

In some countries, people with intellectual disabilities have no legal capacity to act or vote. This should not serve as an excuse not to organise democratic elections for a User Council. It would be also contrary to the purpose of a User Council if service user's parents or legal guardians could be elected to the User Council because they often tend to dominate the discussions in a mixed group. In case of services for people with severe disabilities or complex support needs, it is suggested to create specific Councils of parents and guardians that interact with a Users Council in a structured way.

Good Practice in Germany

The German Ministry for Employment and Social Affairs has supported the publication of an extensive easy-to-read guide for the election of User Councils in sheltered workshops. The legal provision governing these elections details who can vote and who can be elected. It explains the preparation of the election and how it should be carried out, including all relevant deadlines and procedures. If the case arises whereby there are many service users who cannot vote with a voting list, it proposes alternatives for the organisation of these elections. The German law also includes in detail the obligations of service providers to support and finance these elections and to ensure their independence.

Specification of the roles and responsibilities of a User Council

In some countries, the roles and responsibilities of a User Council vis-à-vis the service, the staff and the service provider structures are specified by law. However, reports received by Inclusion Europe show that the actual definition of the work of a User Council is an extremely crucial point. Most important is to ensure the independence of the Council from the interests of the service provider.

Some countries reported that "*User Councils end up in deciding where to go for the next weekend or holidays...*" While even in those situations users seem to be satisfied with the performance of their User Council, this is more an indicator that there are no guidelines about its rights and duties and hardly any possibility to compare its performance with User Councils of other services.

The challenge is to meet organisational performance management requirements, whilst increasing and improving the ways in which service users are engaged and empowered. Having a real power of decision within the service requires making engagement with users integral to all aspects of the work of the service. If user involvement is taken seriously, User Councils are consulted before new services are created (e.g. concerning size, place or architecture), in all aspects of defining their work and objectives, as well as in the practical pursuit of their implementation.

Useful Tool

The King's College in London has published detailed guidelines on "Deciding together: working with people with learning disabilities to plan services and support". In a chapter on changing organizational practice, these guidelines identify some of the key challenges for service providers to include service users effectively in all important key decisions. Perhaps the most important issue identified is "to allow more time for everything". It also recommends the

development of a charter for service users and the need for including all levels of the organisation and its entire staff in this organisational change process.

Keeping User Councils informed

Getting information is very important to be included. People need to be informed, to know what is going on and to find answers to their questions and problems. Those who cannot access information are left out.

Information can be presented in many ways: audio, video or in writing (on printed paper or in electronic format). In order to produce accessible information, there are general criteria to make information easy to understand. These concern the words and sentences used and the way information is presented. For example, jargon or difficult words should not be used, or should at least be explained when they appear, sentences should be kept as short as possible and important information should be repeated when necessary.

In parallel, there are some specific criteria for each way of presenting information. For written information this is called “easy-to-read” format. The criteria for writing easy-to-read texts concern

- the font used (a large size, like Arial 14, should be used, writing in italics or in capitals is not allowed),
- the layout (there should be only one sentence per line, text should be aligned to the left, words should not be hyphenated),
- the construction of the text (there should not be too many layers of subtitles, people should not get more information than they need) and
- the importance of illustrating the text in the right way (no childish symbols when the text is for adults, the same illustration is used to explain the same thing).

Specific criteria exist also for audio information, like not speaking too fast, trying to articulate as clearly as possible and making some clear pauses between two important subjects.

If User Councils are to be involved in all key decisions influencing the provision of the respective service they must be informed in an accessible format about these issues. A lot of information is circulating concerning the management of a service: from formal position papers of the board to internal note services, from verbal information exchanged in meetings to phone conversations, not forgetting e-mails which circulate often between people involved in the decisions regarding the service.

The decision of which of the above information is important for members of a User Council to participate effectively in decision-making is a clear indicator for the need of independent support. While it clearly will not be possible to convert all available information into an accessible format, procedures must be established by which independent supporters determine which information is important for a User Council. The necessary resources then must be available to translate the key information into an accessible format.

Useful Tool

Since many years, Inclusion Europe is producing publications, brochures and leaflets in easy-to-read. People with intellectual disabilities who want to find information which is accessible for them can recognise it by the European Easy-to-Read Logo. More information about this logo and how to use it is available at www.inclusion-europe.org/etr

Inclusion Europe has also developed new “European Criteria for Accessible Information” in the framework of a European project. See www.inclusion-europe.org for more information.

Employ people with intellectual disabilities in the service staff

An important opportunity for augmenting the sensitivity of a service to the needs, wishes and opinions of people with intellectual disabilities is to employ them in paid staff positions wherever possible. This does not only demonstrate the values of a service, it also creates socially valued roles and real employment opportunities for people with intellectual disabilities.

Essential to creating this kind of employment opportunities is the identification of jobs or parts of jobs that can be performed by people with intellectual disabilities. These jobs should not only be limited to cleaning, office support or other menial tasks, but can also extend for example to providing support and care to other disabled people with more severe levels of disability. An important consideration might be splitting of presently existing jobs in different ways or employing more than one person to do a specific task.

Also in this area, consideration should be given to reasonable accommodation for the specific limitations and support needs of a disabled employee. This may involve flexible working times, longer or more frequent training and re-training periods, stronger support arrangements, etc. Clearly, the planning and organisation of these accommodations will require time, flexibility, creativity and – above all – the full involvement of the other service staff in the process.

Good Practice in the United Kingdom

Mencap works with people with a learning disability to change laws and services, challenge prejudice and directly support thousands of people to live their lives as they choose. Mencap campaigns for more people with a learning disability to have the same opportunities to work as other people, and employs a number of people with a learning disability both within the campaigns team and throughout the organisation.

David Congdon, Head of Campaigns and Policy at Mencap describes how Josie, Campaigns Assistant, contributes to and brings a different perspective to the department. “Josie is efficient and helpful in her role but also extremely passionate about the issues affecting people with a learning disability. Her enthusiasm is infectious and when we end up having discussions on bullying or other issues she really adds something to the debate. Her passion for the issues means she's great at going out there, engaging with people and really spreading the word about Mencap and what we do. She reminds us all of why we are doing the work we do, which is to try and get a better deal for all people with a learning disability”.

The Structure of User Councils

Defining the framework for work and responsibilities

One of the first tasks of a User Council will be to agree on a statute or terms of reference for itself. This should specify the working methods and responsibilities of the User Council. It also should define the role and responsibilities of independent supporters.

Regarding its structure it is useful that User Councils agree on regular meetings. For many Councils meeting twice per month seem to be sufficient. It is also useful if the members of the User Council agree on clearly defined responsibilities. Some User Councils have assigned the responsibility for each subject area to two people to ensure mutual support. A specific task is of course the one of the chairperson or speaker of the Council. Also here, a sharing of the task between two members has been positive in several situations.

In relation to the working methods it is essential that a User Council achieves a continuous work rather than only punctual discussions of single topics. This of course requires structured and reliable independent support. It is important that the Council develops a long-term work plan to address structural issues. A system of note and record keeping should be developed and it is very important that all members of the Council are reminded about previous discussions and decisions at the beginning of each meeting. This also requires the availability of a secure place to keep these records and other documents which should be provided by the service.

Useful Tool

The Gateway Clubs published some guidelines for supporting people with a learning disability on committees. They explain that every committee is different, made up of unique, and committed individuals who volunteer their time to support a service. Because of this, certain ways of working will be better for some committees than for others. Many approaches may need to be explored before settling on the final solution. For example, some management committees have a shadow council of people with a learning disability who meet before management

committee meetings to discuss the same agenda, and then meet with the management committee and have input into the decisions made. Other services have self-advocacy or advocacy groups where people with learning disabilities are supported, encouraged and trained by independent persons to speak up for themselves, either as individuals or as a group. These groups tend to have input into management committee decisions.

Representing the rights and interests of all users

One of the more difficult tasks of the User Council members is to ensure that they represent the interests of all users of a service. Careful and structured support is necessary to help members of the User Councils to not only bring up in the discussion what is important for themselves or the problems they are facing.

In order to be able to advocate for others and to make sure that each user of the service is happy with what is being provided, regular consultations with the other users are essential. Members of the User Councils should be supported to discuss with other users their needs and wishes regarding the service provision. The results of these talks should be regularly brought to the User Council's meetings.

A specific challenge may be to know about the needs and wishes of service users with severe disabilities or complex needs. In this case, members of the User Council may lack the skills and experience to communicate with this group of users. Some User Councils have approached this issue by undertaking special trainings in communication methods while others have resolved to consult family members or staff with a long-term relationship with users with severe disabilities or complex needs.

Some specific supports should be created when the service is targeting a specific population of people with more severe disabilities and complex dependency needs. In this case, more efforts and resources will have to be allocated in order to allow the users to make their points and to participate in the decision process.

Good practice in United Kingdom

A Community Learning Disability Team developed a "Total Communication Approach" for working with people who have no speech. The first step was to ask the speech and language therapists to identify common needs of people with communication barriers, being the need for objects of reference, the usefulness of photographs and the effectiveness of signing to accompany or replace speech. Then the staff's day-to-day contacts with service users were adapted. Staff were divided into three "resource teams" to focus on the use of objects of reference, or photographs, or signing; key workers were trained to assess the individuals' levels of understanding in response to the various stimuli; and staff helped to develop a core vocabulary which placed emphasis on communication needed at times of transition (change of activity). Finally, when an individual location had amassed a sufficient core vocabulary, a launch was held in each environment to which the vocabulary applied (canteen, bathroom, etc.).

The success of the project lay in the involvement of all staff, with leadership from their peers (key workers), in addition to the specialists. The enlightened use of time allowed real change without disruption of the necessities of service delivery.

The Tasks of User Councils

Being involved in important decisions

In the past, User Councils tended to be involved only in few decisions regarding a service and we received complaints that they could take decisions only about the food served or about leisure time activities. Inclusion Europe's vision of the involvement of a User Council in service provision goes much beyond that concept. A User Council should be involved in the definition and/or revision of the general objectives of the service, including its aims, profile, size, or the way it is provided.

To make this concept a reality, commitment is needed both on the side of the service provider and of the User Council. Service providers must accept that user involvement in all major decisions affecting a service is an indispensable indicator of service quality. Governments as well as provider organisations accept today that a good quality of services cannot be achieved without strong and meaningful user participation.

There is a danger that user involvement remains tokenistic and that thus the real decisions are still taken without users even though a User Council may exist. This is a strong reason why User Councils need external support that is independent from the service provider interests. Disabled People's Organisation or the independent self-advocacy movement of people with intellectual disabilities can provide this independent support.

Useful Tool

A list of things to do in order for people with intellectual disabilities to be involved in the important decisions is proposed in the publication "Deciding Together". For example, authors suggest

- to hold days to enable people to have their say about what they want from staff;
- to let people who use services decide what should be included in the Annual Report;
- to organise consultation to encourage participants to express their feelings and views freely;
- to support people to build a resource base in which materials which stimulate self-expression can be stored and drawn upon.

Ensuring User Involvement in complaints procedures

A confidential, accessible and effective complaints procedure for the users of intellectual disability services is a key element for protecting them from abuse and exploitation by staff members and fellow service users. A specific challenge is to make this procedure accessible enough to be used by people with intellectual disabilities who feel that their rights may have been violated.

Here a User Council can of course play a central role. Service users may be more likely to report and complain to a fellow user than to a non-disabled staff member who may represent more the interests of the service provider than the interests of the users. However, an adequate training of members of the User Council is a key element for success. All members should receive training and re-training about rights of service users and about how to recognise abuse, discrimination or exploitation. They should be informed about the needs for and consequences of confidentiality and how to support complaining users along their way.

Involvement in staff recruitment

All staff working in support services for people with intellectual disabilities need an understanding of people with intellectual disabilities and a commitment to their empowerment. Therefore at least one member of the User Council should be involved in the recruitment process of all staff members of the service, including the paid Directors. This is specifically important in services where close personal support is provided.

According to research conducted by Inclusion Europe there is little controversy about the question that individual service users should be able to choose their key support person from the existing staff of the service provider. However, staff members and service providers express concern about the general involvement of service user representatives in staff recruitment and appraisal. Since staff members are the key component of human services, Inclusion Europe strongly advocates for a structured recruitment policy and process that ensures that all candidates are interviewed by or in the presence of representatives of the service users. They will be able to provide important opinions on the attitudes and interpersonal qualifications of the candidates that should influence the decision of the recruitment panel.

Useful Tool

The Keyring Living Support Networks have published some “Recruitment Guidelines” in which they explain who may participate in recruitment, how to lead interviews and how to involve service users. Through lists of “do’s” and “don’ts”, these guidelines can help service providers to install, step by step, a procedure which will include people with intellectual disabilities in the recruitment process. It starts with advice on how to attract applicants, then tackles the respect for candidates and develops extensively some interview guidelines, mentioning things like allowing sufficient time between candidates, agreeing on topics to be discussed with the candidates, having the interview questions written in accessible format, etc. Finally, the Keyring guidelines give advice on selecting the right candidate, providing feedback to candidates and proposing a probation period.

Good Practice in United Kingdom

Mencap wants to put people with a learning disability at the heart of all its work. This includes choosing staff. *“We believe that people with a learning disability are often the best judges when it comes to looking at a person’s attitude towards disability. Having a wide range of opinions about candidates helps us to choose the most suitable person for a job. It makes good business sense.”* Involving people with a learning disability in choosing staff sends a strong message. It is a message that says “Mencap values the views and contributions of people with a learning disability”.

Involvement in staff training and appraisal

Continuous and systematic development of staff qualifications is a key characteristic of quality services for people with intellectual disabilities. Service providers should ensure that regarding both in-house training as well as external staff qualification measures, people with intellectual disabilities are involved as trainers. They can ensure that training and qualification are focused on their needs and take into account the ideas of the User Council for the support practice developed by a specific service. Some services even have developed cooperation with schools or universities responsible for the initial training and qualification of staff at different levels to ensure that the ideas of empowerment, self-advocacy and user representation are introduced at a very early stage.

Another key aspect for the further development of staff competencies is the regular appraisal of their work performance. User Councils are an important partner of the service management in this process because they can help to assess how staff is working with and supporting the service users in practice.

Good Practice in Portugal

Some self-advocates went regularly to the Faculty of Human Kinetics at Lisbon University to give a lecture about self-advocacy to students of special education who will be working with people with intellectual disabilities in the future. The self-advocates talked about their own experience as self-advocates, the difficulties in being heard and taken seriously by the professionals and the families. The main objective was to sensitize future professionals to the fact that they should not treat people with intellectual disabilities as if they were not able to choose or to express needs and to decide. This initiative had a huge impact on the students. At the end of the class, almost all of them stated that they were quite impressed and that they never had realized that people with intellectual disabilities could be talking and discussing about their lives and their needs at this level. They also recognised that they had never realised the amount of misconceptions and prejudice they had about people with intellectual disabilities and their abilities. They were all “ashamed” of the little they really knew about intellectual disability – “this we can not learn from the books”, they said. Later, some of the students organised a meeting with professionals and families and invited self-advocates to be there. This was also a very positive outcome.

User involvement in the evaluation of service quality

The evaluation of the service quality is another important area of influence of User Councils. Service providers should choose external and internal evaluation instruments that build their evaluation on user satisfaction as a key criterion of service quality. No service should be evaluated as having good quality if the users of the service are not satisfied.

In the context of service provision, it may be difficult to measure and assess service satisfaction of users with intellectual disabilities in an objective way. Reasons are that many service users may not have clear ideas about how a better and more satisfactory life situation could look like. Some might also feel intimidated when being interviewed by external professionals. A good way to address these issues is the following example of good practice of Nueva in Austria that builds its service evaluation entirely on user satisfaction that is evaluated through interviews conducted by evaluators with intellectual disabilities who are specifically trained in this process.

Good practice in Austria

Nueva is an innovative evaluation process that measures the quality of managed residential opportunities and describes them by means of a quality profile. The special feature of this evaluation process is that it is carried out by people with learning difficulties and special needs. Being service users themselves they know best what they want and need. The Nueva process was developed from the point of view of residents. Nueva's criteria and questions are prepared by people with learning difficulties and special needs on the basis of their own experience as users of managed accommodation. Altogether 24 Nueva trainees have worked for a total of two years on this process. Not all people can be interviewed on a purely verbal basis. That is why there is participative observation as a method for people with severe disabilities or complex needs. Furthermore, every question in the questionnaire, and every choice of answer, is presented in the form of an image. The results of the evaluation are presented so as to suit customers: for customers of managed residential opportunities there is the Nueva Catalogue. For those offering managed residential opportunities there are not only the results of the evaluation of their own establishment but also benchmark data and the possibility of evaluating special interview topics. This is how Nueva offers managed residential opportunity providers numerous possibilities for optimising what they offer, above all in the areas of quality management and accounting, internal and external benchmarking, marketing and positioning and target-group-oriented consumer information. Public services can draw on the quality profiles of individual residential opportunities as the basis for quality control. By means of regional comparisons, provincial comparisons, average values etc., through analysis Nueva can also support social service planning.

Support in assessment procedures and personal future planning

Assessment procedures and personal future planning have a significant impact on the life of a person with intellectual disability. It is therefore important that a person is supported in this process by an independent person of his or her choice. If a service user requests peer support in the process of his/her own needs assessment or personal future planning, a member of the User Council should be available for this purpose.

In the publication "Oi! It's my assessment", People First explains that people with intellectual disabilities usually have very little power in these procedures, despite their important consequences. An assessment of a high support need may, for example, lead to a placement into a segregated high care unit whereas an assessment of a low support need may lead to a situation where not all the needs of a person are met. People First point out that the agendas of carers and parents may be different from the one of the service users. Their experience is that sometimes the needs of carers and parents are met and not those of the people with intellectual disabilities. People First clarifies the need of independent support in this process. This could be done by a representative of the User Council or other people whom the service user trusts. It is necessary that the users have sufficient time to prepare for this meeting and to talk about what they want. The representative of the User Council should be able to explain what will happen at the meeting, what support options could be available and how to make sure that carers and parents do not dominate the meeting.

Good Practice in Finland

Me Itse ry, the Finnish Self-Advocacy Society of Persons with Learning Disabilities, has developed a Guide for Individual Service Planning. The Guide makes clear that the starting point is the satisfaction of a person with his or her present life situation. Individual Service Planning is done in meetings at which only people can participate who are personally invited by the service user. If needs and wishes are identified for which support is not readily available locally, the meeting should explore creative ways to make the wishes of the person with intellectual disability come true.

Necessary Support for User Councils

Ensuring independent support

Independent support for the work of a User Council is one of the most important prerequisites for its functioning. The challenge is that staff members of the service provider start from the knowledge of specialists and from their role as support persons. Thus they often see service users only in their role as recipients of support rather than their whole identity as full and equal citizens of society. Parents and family members may know a person with disability from a different environment, but can nevertheless also have a rather restricted view of the person's abilities.

The ideal support person for a User Council would therefore not belong to any of these groups, but for example work for an independent self-advocacy or disability rights organisation. This might not be feasible in a number of local situations and staff or parents may sometimes be the only resource available to support the User Council. In that case, it will be crucial to have a strong framework and to follow some strict guidelines in order to guarantee a real support and to avoid undue influence.

A strong and close affiliation of User Councils to external and independent self-advocacy or disability rights organisations can be a good balance to these risks of an undue influence. Self-advocacy organisations already exist in most European countries and many are members in the European Platform of Self-Advocates.

Useful Tool

Inclusion Europe has published "Guidelines for Good Support" which explain the role of a supporter during a meeting, propose to write an agreement between the supporters and the self-advocates and insist on the importance of free choice of both parties. This booklet is available at www.inclusion-europe.org.

Several authors from the United Kingdom have produced a multi-media training resource for staff to enable participation, inclusion and choice for people with learning disabilities called "Person-centred active support". Module 3 of this training pack proposes some key issues for the organisation and improvement of (support) practice, with practical advice, for example, a table of "things to consider when developing a support profile".

Training: a corner stone for the work of User Councils

During most of their lives, people with intellectual disabilities are often not encouraged to speak up. Service staff members, parents, professionals or guardians will think they know better what is good for them and will therefore not take the time to offer them choices or to listen to what they have to say. This is one of the reasons why many people with intellectual disabilities have only limited abilities to speak up for themselves. It will thus be essential that members of User Councils are trained, formally and informally.

Therefore an independent training of the members of User Councils can contribute much to their success. This training should not only cover basic advocacy and self-advocacy skills, but also inform people about the basic conditions for the running of their service. Another essential component of such training would be assertiveness in difficult communication situations.

Useful Tool

In “Deciding Together”, Jill Aitchison et al make several proposals in order to help people with intellectual disabilities gain the confidence and skills necessary for engagement. *“One of the ways of helping people to gain confidence in expressing themselves is by setting up peer social or discussion groups facilitated by an external advocate.”*

Good Practice in France

Many services for people with intellectual disabilities in France have created a Council or Committee made of professionals, parents and users. In order to promote a real participation of the users and to encourage those users to find the strength to be involved formally in these committees, the French self-advocacy movement “Nous Aussi” has developed a questionnaire and also some information seminars where people learn to understand better what their role could be in such committee.

Being involved in the independent movement of self-advocates

It has been mentioned before that User Councils need strong support that is independent from the interests of the specific service provider. One of the sources of such support is the independent movement of self-advocates or other disabled people and their families that exists in all countries of the European Union. Without such involvement and contacts a quality work of User Councils can hardly be realised.

It is thus essential that User Councils have the opportunity and are encouraged to meet with groups of people with intellectual disabilities from other associations and services. These exchanges are most easily organised at local level, but User Councils also need to be supported to attend meetings at regional, national or even European level.

Numerous experiences in the past have shown that important initiatives and developments at personal level have been inspired by exchanges between people. It is therefore important to bring people with similar interests in contact with one another and to encourage a systematic exchange of knowledge.

Good practice in United Kingdom

“A well-established housing association supports its tenants’ group which feeds into policy-making committees, thus empowering the tenants. Additionally, individuals are encouraged to join the local self-advocacy group to develop confidence and assertiveness, skills which empower them in many other aspects of their lives.”

Resource list

Setting up User Councils in all services

- Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V.: Arbeitshilfen zur Werkstätten-Mitwirkungsverordnung, Lebenshilfe, Marburg, 2002.
- Fact-sheet from AWHIP – “L’accueil et l’hébergement dans un service spécialisé”. http://www.awiph.be/pdf/documentation/publications/informations_generales/fiches_descriptives/L_accueil_et_l_hebergement.pdf
- Working Document from Brothers of Charity Services South Eastern Region: Advocacy within Brothers of Charity Services.

Specification of the roles and responsibilities of a User Council

- Aitchison, Jill et al.: Deciding together: working with people with learning disabilities to plan services and support. Institute for Applied Health and Social Policy, King’s College, London 2001 – pages 31-38 on “Changing Organisational Practice”
- Mansell, J.; Beadle-Brown, J.; Ashman B. and Ockenden, J.: Person-centred active support. A multi-media training resource for staff to enable participation, inclusion and choice for people with learning disabilities. Pavilion, Brighton, 2004

Keeping User Councils informed

- ILSMH: Make it simple. European Easy-to-Read Guidelines. ILSMH, Brussels, 1998.
- Inclusion Europe: The European Easy-to-Read Logo <http://www.inclusion-europe.org/etr>
- Parker, C.; Goedhard, F. and Gomez, G.: Partners for Better Policies: a Manual for Mainstreaming. Brussels, 2006, page 77-78
- Inclusion Europe: European Criteria for Accessible Information, Inclusion Europe, Brussels, 2008.

Defining the framework for work and responsibilities

- Mendonça, P.: Guidelines for Supporting People with a Learning Disability on Committees. National Federation of Gateway Clubs, London, 1997.

Representing the rights and interests of all users

- Inclusion Europe: Inclusion of people with severe and profound intellectual disability, Inclusion Europe, Brussels, 2003.

Being involved in the important decisions

- Aitchison, Jill et al.: op. cit. , pages 15-23 on “Communication”
- Inclusion Europe: Rules for Meetings and Conferences, Inclusion Europe, Brussels, 2005.

Ensuring User Involvement in complaints procedures

- Aitchison, Jill et al.: op. cit. , pages 15-23 on “Communication”

Involvement in staff recruitment

- Working Document from Key Ring Living Support Networks: Recruitment Guidelines.
- Working document from Mencap: Involving people with a learning disability in choosing staff at Mencap.

User involvement in the evaluation of the service quality

- Inclusion Europe: Achieving Quality. Consumer involvement in quality evaluation of services, Inclusion Europe, Brussels, 2003
- Inclusion Europe: I know what I want! I buy what I want! People with learning disabilities have the power to choose their support services, Inclusion Europe, Brussels, 2003.
- Atempo: Nueva: Qualität kommt an: <http://www.atempo.at>

Support in assessment procedures and personal future planning

- People First England: Oi! It's my assessment. Why not listen to me! People First, London, 1993.
- Me Itse ry: Guide For Individual Service Planning, Me Itse ry, Tampere, 2003

Ensuring independent support

- Mansell, J.; Beadle-Brown, J.; Ashman B. and Ockenden, J.: op. cit., page 87-101 on “Organisation and improving practice”
- Inclusion Europe: Rules for Good Support. Inclusion Europe, Brussels, 2005.
- Parker, C.; Goedhard, F. and Gomez, G.: op. cit., page 72-73

Training: a corner stone for the work of User Councils

- Aitchison, Jill et al.: op. cit. , pages 15-23 on “Communication”
- Parker, C.; Goedhard, F. and Gomez, G.: op. cit., page 63-82.

Being involved in the independent movement of self-advocates

- Aitchison, Jill et al.: op. cit. , pages 24-30 on “Independent Advocacy”
- Parker, C.; Goedhard, F. and Gomez, G.: op. cit., page 70-72
- Inclusion Europe: People with intellectual disabilities can decide more by themselves, Inclusion Europe, Brussels, 2006.

Inclusion Europe

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

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disabilities and their families. Our members are national organisations from 36 countries.

People with intellectual disabilities 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 disabilities 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 disabilities
- 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 disabilities. Inclusion Europe advises the European Commission and members of the European Parliament on disability issues.

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For more information about PROGRESS see:

http://ec.europa.eu/employment_social/progress/index_en.html



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