



Inclusion Europe Position Paper

A European Statute for User Councils in Special Services for People with Intellectual Disabilities

Position Paper

Position Paper adopted at General Assembly 2008

Services are provided for people! The users of services should have a strong influence over and a choice of the services they use. This principle is even more important for people with intellectual disabilities who often depend on their services to a high degree. "Nothing about us, without us" must therefore also be the guiding principle for services for disabled people.

Inclusion Europe therefore calls upon all providers of services for people with intellectual disabilities and all public agencies which commission such services to ensure a democratic representation of users in the management of these services and an effective control by users of the key aspects of service provision. **The existence of such representation and control is an indispensable indicator of service quality.**

An effective way to ensure democratic representation and control by users is the creation of an elected body of user representatives in each service where more than ten people are served in a congregate setting. This body is called in the following text a "User Council", although different terms may be used in different countries and service provision areas. The following provisions describe minimum conditions for the effective work of User Councils:

General Obligations of Service Providers

- Service providers should ensure the existence of and support for User Councils in all services catering for more than ten disabled people under their responsibility, even if no legal requirement for this exists.
- Service providers should ensure that democratic elections for the members of a User Council are held among the users of a service.
- Service providers should develop in cooperation with the User Council a protocol that specifies the roles and responsibilities of a User Council vis-à-vis the service, the staff and the service provider structures.
- User Councils should be involved formally in all key decisions influencing the provision of the respective service. They must be informed in an accessible format about these issues.
- People with intellectual disabilities should be employed in real paid jobs in the service wherever possible. This helps to ensure that service provider structures accommodate the needs of disabled people.

The Structure of User Councils

- User Councils should agree on a statute or terms of reference for themselves specifying their working methods, responsibilities and composition. Service providers should ensure that these statutes are made available in accessible form to all users of that service.
- User Councils should ensure that they defend the rights and interests of all users of a service, especially of those with difficulties to represent themselves. To this end,

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members of the User Council should regularly consult with other users. Service providers should provide the necessary support and means for this consultation.

The Tasks of User Councils

- User Councils should be regularly involved in the definition and/or revision of the general objectives of the service, including its aims, profile, size, and the way it is provided.
- User Councils are an essential element of complaint management procedures in a service. They should be supported to play an active part in ensuring that no abuse or exploitation of users takes place in a service.
- At least one member of the User Council should be involved in the recruitment process of all staff members of the service, including the Directors. This is specifically important in services where close personal support is provided.
- User Councils should be actively involved in training and re-training the employed staff of a service. User Councils know best about the needs of service users and can give an important input in the training and orientation of new staff. Furthermore, the service provider should give priority to external training courses that involve disabled people as trainers.

- 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.

- 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.

Necessary Support for User Councils

- The User Council should be supported by a trained and experienced person who is independent from the service provider.
- The Service Provider should ensure an adequate training for the members of the User Council to ensure that they can effectively participate in staff recruitment, needs assessment and other areas of work of the User Council.
- Service providers should ensure that members of the User Council can meet and exchange with other User Councils in the same city on a regular basis. Members of the User Council should also be supported to participate in external meetings at regional, national or European level with other User Councils or Self-Advocacy Organisations.



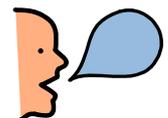
User Councils in Disability Services

What our members think about user councils
in services for people with intellectual disabilities

Services are there to help you.
You should have a choice of the service that you need.
You should have a say in how the service is run.
“Nothing about us, without us” also applies in your service.



Inclusion Europe wants that you have more influence in your service.
We ask all services to make sure that users of services have more influence.
Users should say how the service should be run.
Users should say what services should be provided.
Good services give their users a lot of influence.



“User Councils” are one way to make sure that users have influence in services.
Members of User Councils are elected by all users of a service.
User Councils should exist in all services for more than 10 people.
User Councils should speak for all users of a service.
Sometimes the name for them may be different.

We tell you now how these User Councils should work.

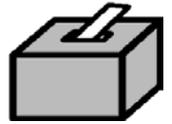




General Duties of the Service

- ▶ All Day Centres, Workshops or Living Facilities for more than 10 people should have a User Council.

This should be done even if the law does not require it.



- ▶ All users of a service should elect the members of the User Council. The service should help users to run that election.
- ▶ The service and the User Council should agree how they work together. They should decide how the User Council works with the staff and with the owner of the service. These rules should be written down.

- ▶ User Councils should have a say in all important decisions. User Councils should receive all necessary information in an easy-to-understand format.



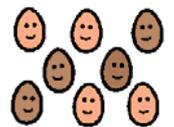
- ▶ People with intellectual disabilities should get real paid jobs in the service. Services for disabled people should not only serve disabled people. They should also employ disabled people in real jobs wherever possible.

How User Councils should work

- ▶ User Councils should agree on rules of how they work. They should agree which of their members is responsible for what. They should agree who speaks for the User Council. The service should make sure that these rules are given to all users of the service.



- ▶ User Councils should speak for all users of a service. They should especially make sure to speak for people who cannot speak for themselves. That means that User Councils should know what the users want. User Councils should talk about this often with the users of a service. Services should give them the possibility for this.



The Tasks of User Councils

- ▶ User Councils should be asked for their views on all questions of the service. They should be asked about
 - * what kind of services are provided,
 - * for how many people are the services provided,
 - * how are the services provided.



- ▶ User Councils should be there to listen to complaints of the users. They should help users when they have a complaint. They should make sure that no user gets a bad treatment because of a complaint.



- ▶ User Councils should have a say about the staff working in a service. One member of the User Council should be involved in all job interviews. This includes all job positions, from the direct care staff to the Directors. It is very important if the service provides close personal support.





- ▶ User Councils should help to train the staff of a service.
They know best what the users need.
They can tell new staff how to do their job right.

- ▶ User Councils should be asked if the service is of good quality. Services should make sure that the opinion of their users is important. Users should always be happy about the services they receive. If users are not happy, the service should be changed.
- ▶ Services should try to find out about the personal needs of all their users. They should help users to plan their personal future. If a service user asks for the help of a peer in this, a member of the User Council should be available.



Support for User Councils

- ▶ The Service should provide a supporter for the User Council. This person should have training and experience. This person should not work for the service.
- ▶ The Service should make sure that members of the User Council get training. They should get training in all areas of work of a User Council.
- ▶ User Councils should meet with User Councils of other services in the same city to talk about their work. Services should make that possible in a regular way. They should also help members of the User Council to go to meetings and conferences for self-advocates in their country.



Respect - Solidarity - Inclusion

On the basis of these fundamental values of the world-wide Inclusion movement, Inclusion Europe fights for the interests of people with intellectual disability in Europe. **Respect** leads to tolerance and the acceptance of people with intellectual disability as valued equal citizens in society. **Solidarity** within societies guarantees necessary quality services, support and protection. **Inclusion** in society is the basis for the exercise of Human Rights and the fight against discrimination.

Inclusion Europe organises the exchange of knowledge between our members, supports them in different areas, and influences European policy in favour of people with intellectual disability, their families and their organisations.

For further information, please contact us or our member society in your country.

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