ESN Working Group on Disability
Meeting 4: Service user involvement

Programme

Place: Radisson Blu Grand Hotel, Sofia (Bulgaria)
Time: 5 April 2016, 9:00 - 18:00

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Service user involvement in public social services

The European Social Network (ESN)’s Working Group on Disability was launched in May 2014, and aims to increase the capacity of public authorities to plan and manage services for people with disabilities in a sustainable and person-centred manner, and to promote independent living and choice and control for service users.

As a follow up to service integration and active inclusion, the working group will look at the topic of service user involvement for people with mild to severe disabilities, including people with mental health problems1.

The meeting will welcome around 20 participants working in social services in public authorities from various European countries, as well as local delegates from Bulgaria and service users. They will present and discuss how public social services include the voices of users, their families and carers, in order to plan, deliver and evaluate services.

The meeting will be organised in cooperation with the Municipality of Sofia, an ESN member.

Co-production and user involvement: Why? How?

Service user involvement has its origins in the disabled people’s and the mental health service user movements2. Specifically, people with learning disabilities developed the concept of self-advocacy so they could speak up for themselves and control their own lives3.

Involving service users and their families in the design, delivery and evaluation of services is key to ensuring that ‘experts by experience’ have a say in how services are delivered. Using users’ experience, skills and expertise at all stages helps to ensure that services respond effectively to their needs. Such an involvement allows people with disabilities to make their own life choices, be included in the community and enjoy independent living. Moreover, involving and listening to users helps to reduce the risk of violence and abuse, and to increase people’s safety and well-being4.

Sometimes user involvement is referred to as co-production5, where the professional guides and supports users to choose the services they need valuing their knowledge and assets6.

For social service managers and commissioners, involving users also means the personalisation of services, while ensuring that people have access to information and advice to make good decisions about their care and support7. This is especially important in regards to deinstitutionalisation. This process, defined as the transition from institutional to

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1 This is notably the case of psychosocial disabilities (e.g. bi-polar disorder, schizophrenia).
4 See ‘Listening to users and carers’, a video from the European Social Network http://www.esn-eu.org/videos/12/index.html
5 Co-production is defined as the ‘active input by the people who use services, as well as – or instead of – those who have traditionally provided them. So it contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else.’ Source: SCIE (2009) http://www.scie.org.uk/publications/briefings/files/briefing31.pdf
7 SCIE (2009), Personalisation briefing: Implications for commissioners http://www.scie.org.uk/publications/ataglance/ataglance06.asp
community-based care and settings, requires new living arrangements, notably housing. Implementation can be facilitated by cooperation between service users, social workers, local and regional authorities, associations and public and private service providers.

Service user involvement can happen at various levels and intensity:

- **Individual**: the person determines their own care and support plan, and purchases their own support with a direct payment;
- **Organisational**: service users and their organisations are involved in organisational decision-making about services (including commissioning and inspecting/evaluating services);
- Involvement in **policy and governance**;
- Involvement in **research and training**;
- Organisations/initiatives led and controlled by users (’service user-led organisations’) provide services, advice and support (such as peer support and self-advocacy).

**The European context**

Service user involvement is enshrined in international and European legislation and guidance, notably the United Nations Convention on the Rights of People with Disabilities (UNCRPD), which recognises that:

- “persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”
- “States Parties shall closely consult with and actively involve persons with disabilities”.

In its 2014 report on the implementation of the UN CRPD by the European Union, the European Commission draws from an *ad hoc* specialist report to stress the importance of, among others,

- Respecting users rights and involving them in decision-making;
- Preventing institutionalisation;
- Creating community-based services.

The above-mentioned expert report highlights that users should be “fully informed” and “actively involved in all decision-making processes” in order, notably, to prevent their institutionalisation.

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A number of associations and networks at European level, representing persons with disabilities, have insisted on the importance to involve users. For instance, the European Network for Independent living (ENIL) drafted a “Co-production factsheet” in 2011\textsuperscript{12}.

### Practice examples of service user involvement: what are we looking for?

In preparation for this meeting, participants have been asked to provide examples using a ‘Practice template’ created by ESN\textsuperscript{13}. Examples should, as much as possible, have been evaluated, be transferable and sustainable.

Examples of practices may include:
- User involvement in researching, designing, commissioning, delivering, evaluating services, policies and governance
- Training and support for staff, people with disabilities, carers and families
- Peer support and self-advocacy
- Co-produced programmes
- Quality monitoring frameworks with service user involvement as a key element
- Support in decision-making (e.g. local committees)
- Collaboration and co-production between professionals and service users
- Practicalities of involvement of people with learning disabilities; e.g. easy-read materials, illustrations, supporters or ‘coaches’.

### Sources


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\textsuperscript{13} Also available in ESN’s members’ area: [http://www.esn-eu.org/members-projects/18/index.html](http://www.esn-eu.org/members-projects/18/index.html)
Programme

Tuesday 5th April 2016

The meeting will take place in the “Library Hall”, situated on the mezzanine floor. You may use the lift or stairs to access the room.

8:45-9:00  |  Registration of participants

9:00-9:30  |  Welcome address and presentation of the situation in Bulgaria
Minka Vladimirova, Director
Sonya Blazheva, Senior expert
Social Affairs Directorate, Sofia Municipality
Tour de table of participants

9:30-09:45 |  Introduction to user involvement in Europe
Practice examples of service user involvement drawn from ESN’s work
Alfonso Lara Montero, Policy Director, European Social Network
Sarah Carr, Mental Health and Social Care Consultant/Associate Professor, UK
Marianne Doyen, Policy Officer, European Social Network
‘Listening to users and carers’ – an ESN video

09:45-10:30 |  User involvement: perspectives of users, service providers and families
Vanya Pandieva, Psychologist and member of the national Centre for independent living (CIL), Bulgaria
Radoslav Krastev, Maria’s World Foundation for people with intellectual disabilities, Bulgaria
Richard Burgess Amos, Gloucestershire Voices, United Kingdom
Susana Rodriguez Moreiras, Manager, Ourense Down Syndrome Association, Spain

10:30-11:00 |  Group discussion
- How is service user involvement organised in your country?
- How can we strike the balance between families’ and users’ wishes?

11:00-11:15 |  Coffee Break

11:15-12:30 |  Policy and governance: user involvement at national, regional and local level
**User involvement in Denmark: Aarhus’ new ‘Development Plan’ for people with disabilities 2014-2017**  
*Carsten Wulff Hansen, Head, Division of services for adults with disabilities, City of Aarhus*

**User involvement: a policy priority for Swedish social services**  
*Karin Flyckt, Coordinator on disability issues, National Board of Health and Welfare (Socialstyrelsen)*

**The user at the centre of the transformation of social care services: the new “A solution for all” plan in France**  
*Daphné Borel, Programme manager, National Fund for Solidarity and Autonomy (CNSA), France*

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<th>Time</th>
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<td>12:30-14:00</td>
<td>Lunch</td>
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| 14:00-14:15 | Presentation of practice examples received from members on service user involvement  
*Sarah Carr, Mental Health and Social Care Consultant/Associate Professor, UK* |
| 14:15-15:00 | Practice examples of service user involvement  
*Mutual Support Groups for people with brain injury*  
*Daphné Borel, Programme manager, National Fund for Solidarity and Autonomy (CNSA), France*  
*Co-produced with Richard Amos* |
| 15:00-15:15 | Coffee break                                                                       |
| 15:15-16:30 | Discussion in two groups: recommendations for service user involvement  
- What would be your recipe for successful user involvement?  
- Follow up of the meeting and discussion about the final product. |
| 16:30-16:45 | Conclusions                                                                        |
| 17:30     | Closing                                                                           |
| 19:30     | Dinner  
*Dinner will be served in the hotel’s restaurant (‘Studio Restaurant’).* |