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'Adapting services for persons with disabilities to new users'

Public authorities' broad strategies to meet the needs of news users
Summary report

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Introduction and definitions

This summary report is based on information and analysis on the situation in their own country provided by the partners in the 'Adapting services to new users' Leonardo project:

- Unapei, France;
- Jugend am Werk, Austria;
- Easpd, Belgium;
- Hand in Hand Foundation, Hungary;
- CECD Mira Sintra, Portugal;
- Learning Disability Wales in partnership with Cartrefi Cymru and Elite Supported Employment Agency, Wales;
- PSOUU Jarosław, Poland.

In this description and critical analysis we shall use the following definitions:

"Current users" are persons with an intellectual disability

"New users" are:

- Persons with a mental disability (that is mental health problems / mental illness);
- Persons with a dual diagnosis (persons with an intellectual disability and a mental disability);

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- Persons in a situation of social exclusion (persons who do not fall neatly into a diagnosis of intellectual disability, or mental disability, or dual diagnosis, but who are vulnerable, distant from the labour market, and who need to be supported by services in order to be socially included).

1. What was the situation for "new users" before they started to be supported by services for persons with intellectual disabilities?

While the project partners come from countries with distinctive political, cultural and social histories there is a remarkable similarity in the situation experienced by 'new users' and people with an intellectual disability before 2000 in each country.

Prior to 2000, any services that existed to support people with a mental disability (mental health) problem and people with an intellectual disability were compartmentalised and separate. Health organisations ran services for people with a mental disability (mental health) problem and social care organisations ran services for people with an intellectual disability. This was the case in Austria, Belgium, France, Hungary, Poland, Portugal and Wales. The extent and effectiveness of these services could vary.

If you had a mental health problem and you were fortunate you might be treated by mental health professionals, in health led services. In France, Poland and in Wales, mental health services were poor with little community level assistance available. If you had an intellectual disability you were supported by social care staff.

If you happened to have both a mental health problem and an intellectual disability the usual position was that your placement was quite arbitrary. If you received any support at all it was likely to be provided by mental health professionals who knew very little about intellectual disability, or with learning disability services who had limited knowledge of mental disability (mental health) issues or you were left completely neglected and dependent on your family.

In Austria psychiatric hospitals would take patients with a dual diagnosis, but the concept itself was not accepted by professionals. In Belgium, services for new users and for people with an intellectual disability were quite mature and well developed, but there was still a lack of connection between health services and social care services and a lack of clarity about how the two distinct services would collaborate to support a 'new user.' In France people who had a dual diagnosis were often supported by organisations with an intellectual disability background, though they would have limited knowledge of mental disability (mental health) issues.

In Hungary, there was little logic or rationale as to where people with a dual diagnosis might receive support from. They could be receiving support from intellectual disability services or mental disability (mental health) services.

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2. What role do the public authorities play in the phenomenon of diversification?

In France, government policy actions have explicitly encouraged social care support for 'new users'. Legislation passed in 2005 in France gave legal recognition to mental disability (mental illness) and granted the right to holistic support for individuals, leading to referral of persons with a mental disability to services for persons with intellectual disability (in the absence of specialist services for persons with mental disability). In the years since 2005, service providers were encouraged to develop a pattern of 'mixed' and 'specialist' services but very little extra funding was provided. The main development was in the field of 'mixed' services, which whilst initially only catering for people with an intellectual disability and some people with a dual diagnosis, now also support individuals with a mental disability (mental illness) and more people with a dual diagnosis. Diversification has therefore occurred, but unfortunately with no adequate support from public authorities in the various relevant areas (funding, training, cooperation with health services, etc.). 'Specialist' services are dedicated solely to people with mental disability (mental illness), but there are very few of them. No services dedicated to the support solely of people with a dual diagnosis have developed.

In Portugal there has been a major, but more organic trend to diversification. Recently there has been a greater tendency for mental health services to be provided in the community and accordingly less reliance is being placed on institutional hospitals. Such institutional accommodation as did exist has been steadily closed down since 2007. A second factor is that Portugal has one of the highest prevalence rates per head of the population in Europe for mental disorder. Both factors have combined to ensure that the barriers between intellectual disability and mental health services were not so substantial. Debate about meeting the needs of people with a dual diagnosis has been encouraged.

In Poland a high profile policy initiative commenced in 2011 to change attitudes to people with mental disability (mental health problems) and to greatly improve services. There has already been some diversification, although the programme is still in its early stages. "No funds (were) secured at any level for the purpose of (…) new users." Funds which actually correspond to the needs of "new users" are obtained mostly by NGO's which are closer to the problem and investigate the actual needs of the users, being in direct contact with them on a daily basis. That has impacted on the creation of appropriate solutions and the implementation of more effective projects that respond to the needs of "new users." These new approaches are slowly sinking into the awareness of the government and, in part, get through to the government programmes.

In Austria, Hungary and Wales, governments have continued to maintain the separation of health and social care. In Austria service providers that specialized in supporting people with mental disability (mental health) problems do not accept people with dual diagnosis or people with intellectual disability as service users. On the other hand, service providers for persons with disability try not to accept persons with mental disability (mental health) problems but do accept persons with dual diagnosis.

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In Belgium and Wales, whilst governments have not explicitly encouraged diversification, they have identified the needs of some 'new users' and encouraged services to work more seamlessly to support them. In Belgium this activity has extended beyond policy statements aimed at people with a dual diagnosis, to creating a multi-agency model of care, joint planning by health and social care agencies through 'Care Circuits' and delivery of targeted services through 'Mobile Intervention Cells'. In Wales, whilst the need for support for people with a dual diagnosis has been acknowledged at a policy level, more practical progress has been made in providing better support and access to services for people on the autistic spectrum.

In Wales, some diversification has occurred as an unintended consequence of government policy. The government has placed an emphasis upon developing a model where local authorities identify need for social care services, then commission those services from a range of organisations by way of inviting tenders. This 'market' model, has encouraged some providers to work with 'new users.' Providers have had a variety of motives in expanding the scope of their service: either through a belief that they can deliver a good service in a field new to them, an aggressive interest in expansion and 'growing' their organisation or a desire to protect the financial solvency of the organisation.

Against this trend in Wales, there has been a barrier to a more fluid and holistic approach to blending the right mix of health and social care services to assist people with an intellectual disability who have other needs. Sometimes if the individual is assessed as having a 'continuing healthcare need', there are then budget arguments between health and social care agencies about who pays for the service to be provided. However, it seems likely that the role that a care manager plays for an individual, which is an established part of Welsh government policy, makes the cooperation smoother than in other countries.

3. Do public authorities provide any support to service providers to face the phenomenon of diversification?

To respond to this phenomenon, public authorities could do a number of things. They could:

- Provide financial assistance, which should be adequate and flexible, and covers all the needs of the user
- Encourage inter-agency collaboration, including between the social care sector and the health sector
- Ensure that appropriate training is provided
- Set standards for the qualification of staff
- Provides evidence-based assessment of what are the needs in terms of services for "new users"
- Promote evaluation of practices, benchmarking, and best practices
- Organise policy dialogue on these issues, as well as consultations of all relevant stakeholders

For countries represented in this project, some encouragement to diversification can be identified in policies, but funding has been absent.

In most countries, other kind of proper support is also absent.

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In Portugal, there is no funding at the moment to support people with a dual diagnosis, but there is at least policy awareness on these issues.

In Wales, if an individual is granted 'continuing healthcare' status, then this can assist the work of a social care service provider in effectively supporting an individual, by paying for and providing additional services. Some local authorities will also provide free training to some service providers on supporting new users or meeting the needs of people with an intellectual disability and other needs.

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