

Future plans

Saturday 28th May 2011 - Panel discussion (with audience participation) on "Policies for a good life in the community: sustaining and improving community services for people with intellectual disabilities in difficult times". This meeting will occur as part of the 11th NNDR Research Conference, May 27-28, 2011, Reykjavik, Iceland. To find out more information about the NNDR conference and to register for the conference please go to:

<http://www.yourhost.is/nndr2011/nndr-and-national-network-conferences.html>

If you are able to join us for the discussion please can you email either Julie Beadle-Brown (Chair) or Chris Fyffe (Treasurer/Secretary)

More information about the work plan

At the last meeting in Rome, The following problem was identified as one on which the SIRG wished to focus over the next two years.

The problem

It seems clear that the first phase of the movement to develop community services for people with intellectual disabilities is coming to an end. Having substantially replaced institutions in many countries, a number of issues are evident:

- The excellent results in terms of improved quality of life achieved in early demonstration projects in deinstitutionalization have often not been achieved in services set up afterwards; many community services achieve mediocre results.
- Instead of a process of continuous improvement in community services, in which pioneer services were succeeded by even better services, and where progress made in reforming accommodation arrangements was extended to include employment, education and leisure, the rate and scope of advance seems to have slowed dramatically.
- The strong ideological roots of deinstitutionalisation and community living in normalisation have been replaced with a more complex framework of ideas which no longer give such a clear agenda for action. Pragmatism appears to have largely replaced the positive ideology that focussed on inclusion and quality of life for people with intellectual disabilities living and participating in communities. It is a characteristic of the present policy discourse that the language of progressive service development is often used to describe regressive policies

and decisions.

- Opportunities to broaden deinstitutionalisation and community living to less affluent countries have had limited success and programmes of institutional refurbishment and rebuilding, funded by the World Bank and the European Union, are taking place in Central and Eastern Europe.
- There are early signs of retrenchment in community services, with larger settings being provided, in the UK, Norway and Australia; in some jurisdictions (Florida in the USA and New South Wales in Australia) new institutions are being built.

Associated with these developments are a number of other features:

- New ideas in policy and service provision, like individual budgets and person-centred planning, are increasingly applied to everyone using services, risking that special needs associated with intellectual disability are overlooked or downplayed.
- The recognition that many of the concerns which have driven improvements in intellectual disability services apply to other services too has led to pressure to 'level down' standards rather than allocate extra resources.
- Strong national leadership is giving way to local priority-setting, by decision-makers who have not been part of the movement for reform and who may be less knowledgeable about it or committed to it.

Proposed project

At the meeting we proposed a programme of work to address these issues:

1. A symposium at the Nordic Association for Disability Research in Reykjavik in May 2011, to discuss the problem, define and characterise it more fully, specify topics on which further work is required and identify researchers to undertake this work.
2. A SIRG symposium at the IASSID World Congress in Halifax, Nova Scotia in July 2012, with papers circulated beforehand, presented briefly and then discussed and criticised.
3. A publication (perhaps a special issue of a journal) presenting the papers, suitably edited and the main points of the discussion, together with a position statement from the SIRG.

Possible topics for discussion

- How can we rekindle our ideological drive and what should this look like?

- Discriminating between service models and practices which enable the achievement of good outcomes for people with intellectual disabilities and their families and those which do not.

- Collating evidence about the progress being made in developing good services and contrasting it with the retrograde developments also occurring.
- Engaging with arguments about equity and cost-effectiveness to ensure correct appraisal by decision-makers of the different options with which they are presented.
- Clarifying and criticising the ideological underpinnings of service development and provision.
- How can we avoid “Re-institutionalisation” of people with intellectual disability when their needs change and in particular in later life as health and support needs changes and ensure that people continue to have a good quality of life in later years?