Workshop 20: European Health Indicators for People with an Intellectual Disability – the POMONA project

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A complex range of co-morbidity, varied aetiology and an increasing evidence base of apparent disparity in health are recognized in people who have an intellectual disability (PWID). This leads to a need to identify appropriate health indicators for this group within the European Union linking to the European Union Health Indicator project, which has established a framework for indicators across the EU.

Description of project
A European Union funded project has been established to identify health indicators for this population. A combination of literature searching, workgroups and wide consultation across member states has been used to identify health indicators. This paper will describe findings from two workshops of representatives of member states and consultation, outlining a framework for indicators appropriate to this group.

Workshop format
1 POMONA European Health Indicators for People with an Intellectual Disability – Professor P.N. Walsh

The increasing global concern over disparity in health care for people with an intellectual disability and the recognition of the particular needs of this population led to the establishment of a pan-European project to identify health indicators. This presentation will address the issues in increasing health needs of this population and the structure of the POMONA project.

2 Health indicators for people with an intellectual disability – Professor M.P. Kerr

This presentation will discuss actual indicators for health in this population comparing the provisional results from the POMONA project with health targets set in the UK and with the public health indicators from the USA.

3 Integration of health indicators: the challenges – Professor M.P. Kerr

There exist major challenge to the integration of health indicators into national datasets and into health surveys. The population of people with an intellectual disability exist as an invisible group in current systems. This presentation will explore the key issues, which may have lead to this situation (1) difficulties in classification, (2) difficulties in identification and (3) a lack of positive discrimination in data gathering. Specific problems in data linkage will also be explored.

4 Interactive discussion – Professor P.N. Walsh

Lesson learned
The development of health indicators in this group will be an important step to assess health care status of PWID across European Member States.

Workshop 21: Future directions for health systems research
Organiser: Peter Groenewegen

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Background
In the 1970s and 1980s the term ‘health systems research’ was generally associated with studies on health insurance, payment systems, cost control mechanisms etc. Traditionally, European health care systems were classified in three groups: national health service systems (also known as Beveridge systems), social insurance systems (Bismarck systems), and the health care systems of the communist countries (Semashko systems), after the fall of communism denoted as transitional systems. It has been argued that this distinction has lost its relevance, because of convergence of the structure of health care systems. Apart from that, health systems research seems to have shifted its focus towards outcomes. In the view of WHO, for instance, health systems research aims to support evidence-based health policymaking and improve the performance of health systems functions. However, with this change of focus, the study of the development of the structure of health care systems has not lost its relevance. It remains important to investigate to what extent aspects of the structure of health care systems show convergence, to what extent they do not, and why.

Aim
The aim of the workshop is to stimulate debate in the workshop ‘Future directions for health systems research’ by proposing an outline of the field of health systems research, by giving an overview of the literature in this area, and by proposing an agenda for future research in health systems research (HSR).

Background
HSR is a multidisciplinary activity. Therefore it disposes of a comprehensive toolkit. The disadvantage is that it does not build on one well-defined theoretical framework. This may lead to misunderstanding of what HSR is about.

Methods
The paper is based on a study of the literature and validated in a workshop of an informal group of Dutch researchers, involved in HSR.

Results
The types of questions that HSR poses, are:

- Type 1 questions where health systems are the ‘dependent variable’ (How have health systems developed, how and in what direction do they change?).
- Type 2 questions where health systems are the ‘independent variable’ (What is the effect of certain institutional structures on the performance of health systems?).

Type 1 questions are answered by means of historical analyses, single or multiple (comparative) case studies, relying on a study of the literature, available documentation, and qualitative methods such as interviews with key informants. Type 2 questions are answered through quantitative research in quasi-experimental designs or international comparisons.

Conclusion
Both Type 1 and Type 2 studies are legitimate branches of HSR that can profit from cross-fertilization. This is particularly true in evaluations of health care reforms, where the sub-domains meet and the type 2 question “Which changes in the institutional structure will improve the performance of health systems?” almost automatically begs the 1 question “And how can this change be successfully implemented in the context of a certain health system?”.