

6. Conclusions

Overall, the activities of the Pomona project indicated that there is no systematic monitoring of the health of people with intellectual disabilities in the EU Member States. Accordingly, there is no foundation for monitoring the health of this sector of the population, for making comparisons across Member States or for tracking trends over time. Thus, key objectives of the Health Information strand in DG-Public Health cannot reliably be achieved on behalf of the estimated five million persons with intellectual disability in the enlarged EU (from May 2004).

Variation in definitions of intellectual disability persist and provide challenges for those in the public health domain who wish to determine the prevalence of this population throughout the Member States. Ongoing efforts by the United Nations to determine the prevalence of disability at international level emphasise the need for harmonisation of the methods used. The outcomes of these efforts, and initiatives at Member State level, will provide valuable feedback regarding the suitability of these methods to determine the prevalence of this hidden population.

Health inequalities and health disparities are evident between those with intellectual disability and the general population. While recent studies have addressed these issues in the United States, no comparable study has been completed on behalf of Europeans with intellectual disability. Arguably, EU policy in respect of the health of this population should make efforts to identify disparities and inequalities and to design, implement and evaluate appropriate interventions to reduce health inequalities.

Programmes supported by the European Union Health Monitoring Systems will continue to provide valid and systematic data on the health of Member State citizens. A foremost programme is ECHI, the European Community Health Indicators. These are currently under revision and, when prepared, will pioneer health monitoring throughout the European Union. And yet the ECHI list contains only one mention of people with intellectual disability – ‘Down’s Syndrome’ – and that is listed as a condition that may or may not be present. Individuals with many other forms of intellectual disability are thus excluded from potential application of the ECHI system. Further, specific health indicators for those with intellectual disability – such as ‘challenging behaviour’ – are not included. Elsewhere, the *Core Indicators Project* in the United States provides a useful template of how such health monitoring can be achieved. However, the heterogeneous nature of the European Union Member States, diverse populations and its many health systems require the establishment of a unique set of indicators for the population of people with intellectual disability in the EU.

In carrying out the present project, national consultations were undertaken in the thirteen participating Member States to identify a set of health indicators for people with intellectual disability. Project partners agreed that disparity was a key criterion in the identification of health indicators for this population and that the ECHI framework could be used as a starting point from which indicators specific to people with intellectual disability could be identified. The draft list of indicators was gradually reduced over the time period of the project from a draft list of thirty to a final agreed set of eighteen.

The aims of the Pomona project were –

(1) To **determine** what health indicators, if any, are in place across the Member States in respect of people with intellectual disability.

A number of sources were examined –

- Literature review
- ECHI template
- National population statistics
- Health interview/examination surveys
- Member State data regarding *Pomona* indicators.

The main finding was that no systematic monitoring of the health of people with intellectual disability was identified. However, the project yielded potential methods by which such data might be collected.

(2) To **consult** on practices, referring to scientific evidence, about optimal indicators for this population.

Through the consensus of all partners, four criteria were developed for the steering group to apply in selecting a list of health indicators –

- Importance
- Disparity
- Usefulness
- Information

While ‘information’ was a criterion, it was not always possible to find available sources. The key and most valuable criterion was ‘disparity’.

(3) To **propose** a set of health indicators for people with intellectual disabilities across the Member States.

The set of 18 indicators that are presented in 5.3 comprise the outcomes of this objective.

In conclusion, the population of people with intellectual disability are disadvantaged in terms of likely health inequalities, and are excluded from current public health monitoring. It is timely and appropriate, therefore, to act and address these important issues at Community level.