

Keynote Address at ACMR 2007.

Title: "Participation and Support: Enabling people with intellectual disability to have a real life"

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Abstract

An individual enjoys the benefits of society by *participating* in that society. Many people with intellectual disability need *support* and accommodations to be able to participate in everyday activities and have a real life. People with severe disability are especially vulnerable to experiencing very limited participation. Individuals living in institutions are likely to be under active and have little or no access to the community. Higher levels of participation are evident in community living, but there remain large differences in participation between individuals. Research on community living shows clearly that two main factors affect the degree of participation in activities: adaptive behaviour skills and support for participation from carers.

This paper looks at participation by people with intellectual disability and the appropriate support needed to facilitate participation so that people can enjoy a full life. A small but significant stream of research involving people with milder disability shows the importance of regular participation as a means of gaining and retaining skills, independence and self-determination. Independence and competence are supported by regular opportunities to apply one's skills. Interestingly, many individuals with milder disabilities seem to do better with *less* support for participation, and thrive on being independent in many areas.

Implementation of an approach to supporting participation known as *Active Support* has offered greater day-to-day participation to people with more severe disability. In this case, however, high levels of support may be needed, and research shows clearly that the more support is available the more participation is achieved.

How do we make sense of these seemingly contradictory research findings regarding support and participation? The issue seems to be one of *matching* support to the person's support needs: that is, providing enough assistance in areas where it is needed without infringing on autonomy by interfering in matters with which the person needs no help. Too much and too little support can both be detrimental. Implications for the design and day-to-day operation of community living services are discussed.

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Agency: Centre for Developmental Disability Studies
Audiovisual equipment: Powerpoint presentation (need laptop and data projector).
Capacity to play a brief DVD