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To the Point - Diabetes information for People with Intellectual Disability and Their Carers

Objective: To describe the perceptions and experiences of living with diabetes as told by people with intellectual disability and their carers and support staff.

Design: Qualitative semi-structured interview study.

Setting: Southeast Queensland, Australia.

Subjects: 67 people - adults with intellectual disability (9), paid carers and support staff of adults with intellectual disability (31), family carers and support staff of adults with intellectual disability (8), service co-ordinators (12), health professionals (6) and other workers in the sector.

Methods: Focus group discussions were held with the participants. Their perceptions and experiences of living with and managing intellectual disability and diabetes were recorded and the themes of the discussions studied.

Results: The findings revealed a number of shortcomings in relation to diabetes care in a population of people with intellectual disability and their carers and support staff. There are higher than average support needs when diabetes is present. There is resentment at intrusion in their lives by diabetes from people with disability. There are feelings of fear and insecurity about diabetes in carers and support staff. Carers and support staff feel that generally they lack knowledge and also lack support from their organizations to manage both the intellectual disability and the diabetes.

Conclusion: The general lack of confidence and knowledge about diabetes makes it difficult for people with intellectual disability and their carers and support staff to function in an effective and satisfying way. There is a need for guidelines.