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ADULTS WITH DOWN’S SYNDROME (81/267)

The National Health and Medical Research Council noted that people with Down’s Syndrome are particularly prone to develop hypothyroidism in adolescence or adulthood, ages when medical assessment is less routinely performed. In a non-complaining adult with Down’s Syndrome it may be difficult to detect decreased alertness and activity, quietness and increased hoarseness of voice. There is, therefore, a need to be alert to the occurrence of acquired hypothyroidism in persons with Down’s Syndrome, and a need for periodic laboratory testing of thyroid function such as by serum thyroid stimulating hormone (TSH) and serum thyroxine (T4).

Attention is also drawn to reports that 40 to 50% of adults with Down’s Syndrome acquire deafness. This is often first manifested by a decline in work performance and co-operation. All Down’s Syndrome people should have regular hearing tests.

ATLANTOAXIAL INSTABILITY IN PERSONS WITH DOWN’S SYNDROME (85/90)

Attention is drawn to articles appearing in Paediatrics Vol 74 No. 1, July 1984 and Mental Retardation, August 1984 regarding the participation of persons with Down’s Syndrome in USA Special Olympics.

In March 1983, Special Olympics Inc. issued a directive requiring all persons with Down’s Syndrome wishing to participate in sports involving stress on the head and neck (gymnastics, diving, pentathlon, butterfly swimming, diving starts in swimming, high jump, soccer and warm up exercises) to have a medical examination, lateral view x-rays of the upper cervical region in full flexion and extension and certification by a doctor that the examination did not reveal atlantoaxial instability or neurological disorder. No problems had been encountered in the 15 seasons of Special Olympics, and this was a purely preventative action.

The incidence of atlantoaxial instability among persons with Down’s Syndrome has been reported to be between 10 and 20%. When this instability results in subluxation or dislocation of C1 and C2, the spinal cord may be injured. This is a rare but serious complication. Enquiry reveals that no such cases have been treated in NSW Spinal Units.

It is recommended that staff be aware of this abnormality, the frequency of occurrence and the potential dangers. In addition it is recommended that persons with Down’s Syndrome should be encouraged to engage in sports that do not involve stress on the head and neck; for those sports that do, the rules should be modified; e.g. no heading of the ball in soccer, in-pool starts from swimming races. Should such persons choose to participate in high risk sports, lateral view x-rays of the cervical region in neutral, flexion and extension positions within their tolerance should be done before beginning training or competition.

PROVISION OF SERVICES TO PEOPLE WITH AN INTELLECTUAL DISABILITY & MENTAL ILLNESS - ADHC/Health Memorandum of Understanding (PD2011_001)

PD2011_001 rescinds PD2005_039.

PURPOSE

This policy:

1) Introduces the NSW Memorandum of Understanding between NSW Health and Ageing, Disability & Home Care (ADHC), Department of Human Services NSW.
5. DEVELOPMENTAL DISABILITY

2) Outlines what is required by both NSW Mental Health Services and Ageing, Disability & Home Care (ADHC) service staff in implementing the joint Memorandum of Understanding and accompanying Guidelines.

MANDATORY REQUIREMENTS

The Memorandum of Understanding is a joint agreement outlining collaborative service provision by NSW Health and Ageing, Disability & Home Care, Department of Human Services NSW for improving access to services for people with an intellectual disability and a mental illness in NSW.

The joint agreement (MOU) and the Guidelines by which it will be implemented aim to improve the interaction between the two government agencies by:

• Working to improve access to mental health and disability services.
• Ensuring no person from this population group experiences any discrimination in accessing services.
• Working to improve access and treatment outcomes for this population group and the support offered to their family and carers.
• Enabling working relationships based on a shared sense of responsibility for the provision of services to people whose needs overlap both agencies.
• Ensuring staff members are made aware of, and supported to access, resources and training that will further assist this population group.
• Developing parameters for a model for the sharing of data and information.

IMPLEMENTATION

Health Services

All Mental Health Services are required to work in collaboration with Ageing, Disability & Home Care service staff to:

• Establish local Area/Regional Joint Forums to assist in the implementation and ongoing facilitation of this Memorandum of Understanding and Guidelines.
• Ensure that the Terms of Reference, list of members and quarterly reports for the local Area/Regional forum are provided to the Intellectual Disability Mental Health Working Group (IDMHWG).
• Ensure that the work of the local Area/Regional Joint Forum is in accordance with the MOU and Guidelines such as:
  o Promoting access to services through a range of strategies, such as collaborative service delivery.
  o Developing local protocols detailing the precise mechanisms by which each agency will request the involvement of the other for acute care and immediate response.
  o Providing resolution to any dispute that may arise and identifies the mechanism for escalation on issues that cannot be resolved via the local forum.
Roles and responsibilities of all mental health service staff:

To ensure their work practices are consistent with the principles outlined in the Memorandum of Understanding and accompanying Guidelines.

**NSW Department of Health representatives**

Members of NSW Health and representatives of Area Mental Health Services will provide ongoing oversight of the implementation of the MOU and Guidelines in their role as members of the Intellectual Disability Mental Health Working Group (IDMHWG). It is the role of the IDMHWG to monitor the progress of this agreement.

The IDMHWG will also lead the implementation of the Memorandum of Understanding and will monitor and evaluate its success 18 months from the date of commencement. The results from this evaluation will be fed into the Policy review process.