

**Investigation highlights the importance of adequate consent  
protocols for intellectually impaired patients  
19HDC00666**

Health and Disability Commissioner Morag McDowell recently finalised an investigation concerning the care provided by New Zealand Family Planning Association Incorporated (Family Planning), to a young person diagnosed with fetal alcohol spectrum disorder (FASD) and attention deficit hyperactivity disorder (ADHD). The young person had been assessed by a specialist clinician who considered that she had the mental capacity of a child, was unable to understand the consequences of sexual conduct, and was at risk of sexual exploitation. When she was 13 years old, she had a contraceptive implant inserted with the support of her family.

When the young person was 16 years old, she consulted a nurse at Family Planning to have the implant removed because she was unhappy with its side effects. During the appointment, the young person's grandmother and court-appointed guardian contacted Family Planning to advise that the young person did not have capacity to make the decision to have the implant removed. The grandmother asked the nurse not to remove the implant that day, and to wait until she provided the nurse with information about the young person's impairment including the specialist assessment. However, despite having little experience in FASD, after speaking to the young person and consulting senior Family Planning staff, the nurse deemed the young person competent to make her own decision. The nurse removed the implant and gave the young person condoms for ongoing contraception.

Ms McDowell affirmed her support for the vision of the New Zealand Disability Strategy, which states:

“New Zealand is a non-disabling society — a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen.”

She also noted that a determination of lack of competence is an important constraint on the right to make decisions, and reasonable care should be taken when deciding issues of competence, to ensure a balance between allowing consumers to make their own decisions, and protecting them from harmful consequences if they make decisions when they are not competent to make an informed choice and give informed consent.

Right 7(1) of the Code gives consumers the right to make an informed choice and give informed consent to treatment. That right can be exercised only by those with sufficient decision-making competence. The Code presumes that consumers are competent, as Right 7(2) states:

“Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.”

Competence can be rebutted by evidence to the contrary. Lack of cognitive functioning is common in serious neurological and psychiatric disorders, but many people suffering from such disorders will still retain some or all legal capacity. Right 7(3) of the Code states:

“Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.”

Right 7(4) gives a framework for providing services to consumers who are incompetent and so unable to make informed choices and give informed consent themselves.

For providers to know whether Rights 7(1), 7(3), or 7(4) apply, they must either presume competence or, if there are reasonable grounds for displacing a presumption of competence, undertake an adequate competence assessment to inform a determination of competence, diminished competence, or incompetence. Ultimately, as competence is decision-specific, the provider must determine whether the consumer has the capacity to make the particular decision they are faced with at that time.

The Commissioner considered that Family Planning did not have in place adequate protocols to deal with the situation of assessing capacity in a young person with intellectual impairment, and that its staff failed to recognise the red flags that should have led to a delay in removing the implant (to allow the gathering of information to inform the competency assessment).

Accordingly, the Commissioner found that Family Planning breached the Code by failing to provide services with reasonable care and skill.

Morag McDowell was critical of the nurse’s conduct, and considered that the nurse should have deferred her conclusion about the young person’s competence, and her decision to remove the contraception, until the issues raised by the young person’s grandmother had been clarified, both to enable a complete assessment of the young person’s competence, and to inform appropriate advice and treatment.

Ms McDowell said:

“This case demonstrates the need for healthcare providers to understand the impact of neurocognitive impairments, including FASD, on capacity for decision-making. People with such impairments present uniquely, with their own profiles of strengths and impairments. As has been seen in this case, individuals may present with subtle impairments that can be overlooked or underappreciated by those providing them with care.

Providers of health and disability services must assess capacity to consent in a person with neurocognitive disabilities in the ordinary way using the necessary criteria. However, providers should also have the knowledge and skills to identify when in-depth assessments may be necessary to fully understand how

well capacity in an individual with neurocognitive impairments is functioning. For example, individuals with FASD may communicate and appear to understand decisions, but have difficulty foreseeing the consequences of decisions. Each assessment should depend on the nature of the procedure being consented to, and it may be appropriate for providers to defer assessing capacity to a more experienced colleague or provider with relevant specialist expertise.”

Ms McDowell recommended that Family Planning arrange ongoing training on the issues in the report; provide its revised guidelines on informed consent, and review the operation of the revised guidelines; amend its policy for record-keeping to include assessments undertaken when determining competence, and the reasons why a person has been deemed competent; undertake an audit of the documentation of assessments of capacity; and apologise to the young person and her grandmother.

Ms McDowell recommended that the nurse undergo training on informed consent and assessment of competence, including legal obligations; undergo training on the maintenance of clinical records; review the Nursing Council of New Zealand Code of Conduct for Nurses, particularly in regard to the requirement to recognise and work within the limits of her competence; and apologise to the young person and her grandmother.

**4 April 2022**