International studies found that parents with learning disabilities are 15 to 50 times more likely to have their children removed and placed in care than other parents. Women with intellectual disability may present late to antenatal care due to a failure to recognize the pregnancy or a lack of knowledge, poor contraceptive use and difficulties or emotional responses should not be confused with incapacity.

While there is little research on crisis pregnancy and intellectual disability, low sexual knowledge, poor contraceptive use and difficulties or emotional responses should not be confused with incapacity. The draft Heads of legislation aim to set out conditions for those who are dealing with patients whose decision-making capacity is in doubt and assess their capacity to consent. Inability to lucidity offered by the legislator, provides caregivers, comply with these conditions. The person acting on behalf of a person whose decision-making capacity is in doubt must take steps to establish that the person lacks capacity in the matter, and having done so, must believe that the act is in the person's best interests.

Some should be cautious to implement the draft Heads of legislation and to ensure that a right to promote understanding and develop capacity have been taken. This may include using simple language and/or images, breaking down the information into easily understood points and using specialist interpreters to aid communication.

Assumptions should not be made about a person's capacity to consent based on their appearance or behaviour; communication difficulties or emotional responses should not be confused with incapacity.

A standard assessment protocol (considered in a code of practice/ guidelines) would reduce bias and introduce consistency in the way that mental capacity assessments are conducted.

Where a person lacks capacity, guidance should be provided to the decision-maker on how to act in the person's best interests.

Pregnancy and intellectual disability

- Women with intellectual disability often experience negative attitudes from those close to them and from service providers when they become pregnant.
- While there is little research on crisis pregnancy and intellectual disability, low sexual knowledge, poor contraceptive use and vulnerability to abuse puts women with intellectual disability at risk of crisis pregnancies.
- Women with intellectual disability may present late to antenatal care due to a failure to recognize the pregnancy or a lack of appropriate and accessible services.
- Pregnant women with intellectual disability may try to keep their pregnancy a secret because they fear they will not receive family support or have to give up their baby.

Practical Help

- A consistent finding in the international literature is that mothers with intellectual disability experience poverty, anxiety and social isolation and tend not to have the necessary supports in place to cope with difficulties that they encounter as parents.
- Another study has shown that mothers with intellectual disability were not strongly related to parenting success or failure, but professional support and support from a social network were.
- International studies found that parents with learning disabilities sue 15 to 50 times more likely to have their children removed and placed in care than other parents.

Features of effective parenting and parent-teacher services

- Spedally tailored materials / literature and accessible services can help women to understand the implications of parenthood and provide advice on how to cope.
- Early intervention by services to identify a woman’s support needs can improve the standard of care she receives.
- Independent advocacy and formal support can overcome negative attitudes of a woman’s partner / family / service provider towards pregnant teenager parents with intellectual disability and reassure the child when they are using healthcare and support services.
- Support should be provided on a long-term basis and should focus on redeveloping and developing the parents’ own skills, confidence and competence.
- Parent training programmes should teach a broad range of parenting skills, such as money management, health and safety, behaviour management and accessing services.

Research on intellectual disability and crisis pregnancy, parenting and sexual health for caregivers, health professionals and service providers

This is a summary of research on sexual and reproductive health and intellectual disability, designed especially for healthcare professionals or people working with or caring for people with intellectual disability.

What is This Research Summary About?

This legislative summary key research findings from a literature review commissioned by the Crisis Pregnancy Programme of the National Disability Authority. The literature review was written by independent researcher, Joan O’Connor.

This research summary describes the challenges faced by people with intellectual disability in the context of crisis pregnancy with regards to managing their sexual and reproductive health and accessing health and social work services. It describes international best practice, outlining how service providers, policymakers and legislators can develop strategies address these challenges.

The summary also presents the complex legal and practical issues that surround capacity to consent to sexual relationships and make healthcare decisions. These findings will be of particular relevance to policymakers and legislators in Ireland as they consider the development or changes to the sex education curriculum.

Want to Read More?

- The full research report - Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy - is available online for people with disabilities. This report includes a summary of the key research findings.

Access to Accommodation Services

The following NDA publications published in 2010 are available from www.nda.ie

- Women with Disabilities: Barriers and Facilitating Access to Accommodation Services During Pregnancy, Childhood and Early Motherhood

- Literature Review and Women with Disabilities: Policies Governing Provision and Practice in Service Provision in Ireland During Transition to Independent Living Services and Autism Spectrum Disorders

- The Strengths and Weaknesses of Publicly Funded Irish Health Services Provided to Women with Disabilities in Relation to Pregnancy, Childhood and Early Motherhood.
The Scheme of Mental Capacity Bill 2008, were published for consultation in Poor sexual knowledge can make women with intellectual disability vulnerable to abuse and/or crisis pregnancy. People with intellectual disability have lower levels of sexual health knowledge than the general population. Some studies report poor provision of sex education to people with intellectual disabilities. Poor sexual knowledge can make women with intellectual disability vulnerable to abuse and/or crisis pregnancy. People with intellectual disability have lower levels of sexual health knowledge than the general population. Some studies report poor provision of sex education to people with intellectual disabilities. 

− Low sexual knowledge has implications for assessment of capacity to consent to sex in that many jurisdictions judge a person's capacity to consent by his or her level of understanding of sex and its outcomes.

Legislating for Sexual Relationships

− There is no one standard approach to assessing capacity to consent to sex – some jurisdictions state that a person who lacks capacity to consent to sexual activity should be presumed to lack capacity to consent to medical treatment. Legislation governing capacity to consent to medical treatment

− People with intellectual disability are more likely to be prescribed oral contraceptives than the general population. Sterilisation is more common among women with intellectual disability. Contraception

− Some studies suggest that contraceptive choice for women with intellectual disability is influenced by an assumption that they are at a greater risk of pregnancy than the general population. 

− Poor knowledge about appropriate sexual behaviour or lack of knowledge with respect to what constitutes abuse can make people with intellectual disability more vulnerable to abuse and sexual exploitation. These vulnerabilities can also make the reporting of abuse or sexual exploitation more difficult.

− Some studies report poor provision of sex education to people with intellectual disabilities. 

− Women with intellectual disability are more likely to be prescribed long-term or low-maintenance contraceptive methods and less likely to be prescribed one contraceptive method of contraception. While this may be true for some women, research suggests that service providers do not always explore a woman’s ability to be involved in the decision.

− Some research found that women with intellectual disability have contraceptive needs similar to those of the general population, and standard contraceptive consultations can be modified to meet the needs of women with intellectual disability.

− Where a person is deemed to be unable to consent to medical treatment legal provisions in Ireland allow another person to make a healthcare decision for that person.

Contraception

Use of contraception
− Women with intellectual disability are more likely to be prescribed long-term or low-maintenance contraceptive methods and less likely to be prescribed one contraceptive method of contraception. 

− Cognitive ability has been linked positively with using birth control: the higher the cognitive ability the greater the likelihood of using birth control.

− A woman's long-term environment was chosen to facilitate contraceptive use. An institution was in an institution was associated with using contraception, particularly institutions in which sexual relationships were prohibited and where contraceptive use was required.

− Careful consideration of each individual’s circumstances is essential when discussing contraceptive options.

Relationships and Sexuality Education

Sexual activity
− While historically sexual activity of people with intellectual disabilities was suppressed, the right of people with disabilities to sexual expression is now beginning to receive more attention in a policy and legal context, and in service provision.

− Research shows that people with disabilities are unlikely to be involved in sexual activity.

− People with intellectual disability are particularly vulnerable to abuse.

Sexual education and knowledge
− Sexual knowledge among people with intellectual disability is generally lower than that of the general population, although it is not clear if this is due to intellectual impairments or lack of education – in some studies only half the population with an intellectual disability had ever received sex education.

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