

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



National Disability Authority
Údarás Náisiúnta Míchumais

crisispregnancyprogramme



What is This Research Summary About?

This leaflet summarises key research findings from a literature review commissioned by the HSE Crisis Pregnancy Programme (formerly the Crisis Pregnancy Agency) and 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 in different jurisdictions 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 service providers in Ireland in light of the UN Convention on the Rights of Persons with Disabilities and changing Irish legislation on mental capacity.

It is to be hoped that the findings from the research will contribute to the development of national policy and legislative structures, standardised care protocols and accessible, tailored services, to ensure that the sexual health, pregnancy and decision-making and parenting support needs of people with intellectual disability throughout Ireland are met.

What Does the Research Tell Us?

Some of the main points from the research are:

- According to the National Disability Survey 2006, there are 50,400 people diagnosed with an intellectual disability living in Ireland, 40% of whom are women.
- A crisis pregnancy is defined as 'a pregnancy which is neither planned nor desired by the woman concerned and which represents a personal crisis for her'. It is important to state that not all pregnancies experienced by women with intellectual disability are assumed to be a crisis pregnancy.
- Information and research on sexuality, relationships, pregnancy, crisis pregnancy and parenting in relation to people with intellectual disability is limited, and this is particularly true with regard to pregnancy and crisis pregnancy.
- People with intellectual disability vary greatly in their experiences, capabilities and wishes. Therefore, generalisations about what is best for people with intellectual disability must be treated with caution. Also, definitions of disability vary across jurisdictions, making comparative analysis difficult.
- Negative perceptions are still commonplace about the sexuality of people with intellectual disability and the prospect of them becoming pregnant or parenting a child.
- 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.

- Proxy decision-making, where paid carers or relatives make decisions on behalf of a woman with intellectual disability, is commonplace in the area of women's reproductive health.
- Draft Heads of new legislation on mental capacity, The Scheme of Mental Capacity Bill 2008, were published for consultation in 2008. The draft Heads propose that there should be a presumption of mental capacity and that a person would not be treated as unable to make a decision unless all practicable steps to help him or her to do so had been taken without success. This would include decisions in relation to medical treatment (such as contraception). The draft Heads provide for the appointment of a Personal Guardian to make decisions in the best interests of the individual concerned in relation to those matters where a person lacks capacity.
- Irish legislation governing sexual offences criminalises specific sexual acts, including intercourse, with people coming within the legal definition of 'mentally impaired' unless they are married to each other. Therefore it may be an offence to engage in sexual activity with a person with an intellectual disability even if a person consents and is capable of consenting.
- The ability of people with intellectual disability to make healthcare decisions, improve their sexual knowledge and manage relationships and parenting can be improved by accessible and tailored services and support.
- Parents with intellectual disability face challenges related to isolation, poverty and lack of support services.
- While solid support, especially from family, can assist those with intellectual disability to parent successfully, many children of parents with intellectual disability are placed in care.

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 higher levels of cognitive functioning are more likely to be engaged in sexual activity.
- People with intellectual disability are particularly vulnerable to sexual 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 capacity or a lack of education – in some studies only half the population with an intellectual disability had ever received sex education.
- 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.
- 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.

Improving sexual knowledge for people with intellectual disability

- Research has shown that given the appropriate materials and support, women with intellectual disability do have the capacity to increase their sexual knowledge.
- Sex education can improve the decision-making capacity of a person with intellectual disability by increasing his or her understanding of relationships, sexual behaviour and the consequences of sexual activity.
- Sex education should be provided at an appropriate level over a long period and with one-to-one follow-up.
- Suggested sex education topics for people with disability include social skills and assertiveness training, public versus private situations, safer sex practices, sexual exploitation and the difference between a friend and a boyfriend / girlfriend.
- Individuals with intellectual disability should understand that sex is never compulsory. It is important that sexual health education addresses issues of power and exploitation in sexual relationships.
- Trained staff in residential and day services can play an important role in promoting sexual health education among service users with intellectual disability.

Legislation Governing Capacity to Consent to Sexual Relationships

Legislating for sexual relationships

- Jurisdictions have enacted various laws providing different levels of protection from sexual exploitation to adults with intellectual disability at risk. Legislation attempts to balance the right to sexual expression and autonomy while protecting people who may lack capacity to consent from sexual exploitation and abuse.
- Protective legislation aims to provide protection from abuse and is based on the assumption that people with intellectual disability lack capacity to consent to sex. Legislation framed within a 'diagnostic approach', such as that in some US states and here in Ireland, determines capacity to consent to sexual relationships by the diagnosis and its definition. Protective legislation can be at odds with other rights-based legislation and may curtail a person's right to be sexually active.
- In legislation framed within a 'functional approach', such as that in England and Wales and some states in Australia, capacity to consent is articulated in terms of capacity to understand the nature and consequences of the act and a person's ability to communicate his / her choices. Legislation with a functional approach attempts to set down criteria by which a person with intellectual disability can be deemed as capable of consenting to sex.

Assessing capacity to consent to sexual relationships

- There is no one standard approach to assessing capacity to consent to sex
 - some jurisdictions state that a person who understands what sex is can consent to sex, whereas other jurisdictions require a person to understand sex and its potential consequences, such as pregnancy and sexually transmitted infections.

- A diagnostic approach involves making assumptions about a person's capacity to consent based on their disability, so that a person may be deemed unable to give consent to any sexual activity.
- A functional approach to capacity assessment accepts that an individual may be capable of consenting to some relationships and not others.

International best practice provisions in legislating for and assessing capacity to consent to sexual relationships

- Best practice in assessment of capacity uses a 'functional approach' to assess capacity on an issue- and time-specific basis
- Good practice in assessment of capacity to consent to sexual relations includes key assessment criteria such as: an understanding of the nature of the act; an understanding of its consequences; the ability to communicate an individual's choice to engage in the act.
- Support and assistance should be provided to ensure those with communication difficulties are enabled to communicate their views and choices.

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 oral contraceptives than the general population. Sterilisation is more common among women with intellectual disability.
- 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 living environment was shown to affect contraceptive use. Living in an institution was associated with using contraception, particularly institutions where sexual relationships were not prohibited and where contraceptive use was required or advised.

Contraceptive decision-making

- People with intellectual disability are often not consulted about contraceptive decisions or may not have the effects or possible side-effects of contraceptive methods explained to them.
- Some studies suggest that contraceptive choice for women with intellectual disability is influenced by an assumption that they are unable to manage certain methods 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 that standard contraceptive consultations can be modified to meet the needs of women with intellectual disability.

International good practice in contraceptive provision

- Medical professionals should approach a contraceptive consultation with a person with intellectual disability as they would a standard contraceptive consultation, taking into account medical and lifestyle factors and the client's own preference and beliefs / values. At the same time, the service provider should take into account and attempt to meet the specific needs and capabilities of the client.
- People with intellectual disability should be given appropriate information and support to help them be involved in their contraceptive decision-making.
- Longer consultation times allow for the extra work that may be needed to involve a person with intellectual disability in contraceptive decision-making.
- Sex education and / or family planning counselling should be provided by appropriately trained medical professionals, to promote a person's capacity to choose and consent to contraceptive treatment.

Capacity to Consent to Healthcare Decisions

Assessing capacity to consent

- Informed consent generally requires that the patient has received enough information about the healthcare decision, has the capacity to make a decision about the treatment and can voluntarily choose to accept or decline the treatment.
- The current lack of legal structures in Ireland relating to capacity to consent means that health professionals must use their personal judgement in assessing a person's capacity to accept or reject treatment and in determining how to proceed if the person lacks the capacity to consent to treatment.
- UK research found that knowledge of capacity assessment issues among medical professionals was inadequate. Given the need for guidance in Ireland there is likely to be a greater challenge for Irish medical professionals in assessing capacity.
- Assessment instruments based on factors such as mental age have been critiqued in the literature; instead, 'functional' assessments are favoured, where capacity is judged in terms of a person's capacity to make a particular decision at the time it needs to be made.

Legislation governing capacity to consent to medical treatment

- 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.
- Draft Heads of new legislation - The Scheme of Mental Capacity Bill 2008 - propose to change how capacity to consent would be assessed in Ireland. This Bill, if approved, would have implications for healthcare providers and guardians, who would have to know and comply with the legal guidelines around capacity to consent.

- 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 assessing their capacity to consent. Immunity from liability is offered by the legislation, provided 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.

Best practice provisions in capacity legislation and assessment

- A person should be assumed to have the capacity to make a decision unless it can be shown that they do not.
- Capacity should be viewed as decision-specific and time-specific, so that capacity to consent must be assessed each time a decision is to be made and not be assessed according to previous capacity assessments or medical history.
- Emphasis should be placed on the quality of the decision-making process, to ensure that all steps to promote understanding and develop capacity have been taken. This may include using simple language and / or images, breaking down the information into easy-to-understand 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 (contained 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 Parenting

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 put women with intellectual disability at risk of crisis pregnancy.
- Women with intellectual disability may present late to antenatal care due to a failure to recognise the pregnancy or a lack of appropriate and accessible services.
- Women with intellectual disability may try to keep their pregnancy a secret because they fear unwanted family interference or having to give up their baby.

Parenting

- 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.
- Family support has been shown to be crucial in determining the parenting success of people with intellectual disability. Level of intellectual disability was 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 are 15 to 50 times more likely to have their children removed and placed in care than other parents.

Features of effective pregnancy and parenting services and supports

- Specially tailored materials / literature and accessible services can help women to understand the implications of pregnancy and parenthood and make choices accordingly.
- 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 a pregnant woman or parent with intellectual disability and reassure the client when they are using healthcare and support services.
- Support should be provided on a long-term basis and should focus on reinforcing and developing the parents' own skills, competence and confidence.
- Parent training programmes should teach a broad range of parenting skills, such as money management, health and safety, behaviour management and accessing services.
- Clear and coordinated referral procedures between health and social care providers enable the needs of parents with intellectual disability and their children to be identified.

Useful Information and Contacts

HSE Crisis Pregnancy Programme
4th Floor
89-94 Capel Street
Dublin 1
Tel: 353 1 814 6292
Fax: 353 1 814 6282
Email: info@crisispregnancy.ie
Web: www.crisispregnancy.ie

Sexual Health Resource Library

A free sexual health resource library, funded by the Crisis Pregnancy Programme, is available to those working within the HSE South region. There is a broad range of resources available for those working in the area of sexual health and intellectual disability. For more information please contact your local Health Promotion Offices within HSE South.

South East:

Moira Germaine

Senior Health Promotion Officer
Tel: 059 914 3630

Cork:

Sharon Parkinson

Senior Health Promotion Officer
Martin Grogan
Health Promotion Officer
Catherine Byrne
Health Promotion Officer
Tel: 021 492 1641

Kerry:

Maire O'Leary

Health Promotion Officer
Tel: 064 667 0773

Practical Help

CHANGE: Books, tapes, pictures and publications on sex and relationships.
www.changepeople.co.uk Tel: 00 44 113 388 0011

fpa: All about us – CD ROM on sexual and personal relationships for people with learning disabilities.

Talking together about growing up – Workbook for parents of children with learning disabilities who are approaching puberty.

www.fpa.org.uk Tel: 00 44 845 122 8600

Family Planning, New South Wales: Love and Kisses – DVD showing a compilation of interviews of people with intellectual disabilities telling their own stories about their reproductive and sexual experiences.

www.fpnsw.org.au/disability/

McCarthy, M. and Thompson, D. (1998) **Sex and the 3Rs: Rights, Responsibilities and Risks.** A sex education package for working with people with learning difficulties. Pavilion Publishing.

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 download at www.nda.ie or www.crisispregnancy.ie

An 'Easy to Read' edition of the report is also available to download at www.nda.ie and www.crisispregnancy.ie

HTML versions of this research summary, the main report and an easy-to-read edition are also available at www.nda.ie

The following NDA publications are available from www.nda.ie –

Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood.

Literature Review and Women with Disabilities: Policies Governing Procedure and Practice in Service Provision in Ireland During Pregnancy, Childbirth and Early Motherhood.

The Strengths and Weaknesses of Publicly Funded Irish Health Services Provided to Women with Disabilities in Relation to Pregnancy, Childbirth and Early Motherhood.