Building Capacity to Choose

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My Objective

To provide participants with the knowledge they require when supporting people with disabilities to make choices regarding their relationships.
Building Capacity to Choose

The UNCRPD

- Quality
- Non-Discrimination
- Ability
- Building capacity
- Law and policy
- Equal status approach
The E.N.A.B.L.E. model is a method or tool that professionals can use to support an individual as they make choices and decisions about their sexuality and intimate relationships.

It ensures that the process is governed not by the beliefs and values of any one individual or organization but by a set of parameters that objectively covers every aspect of the decision making progress.

This ensures that best practice informs local practice resulting in the relevant persons needs been met professionally and comprehensively.
The model recognises the need to balance the information, guidance and support which is required to make informed decisions, with the liberty to make the same decisions as others, without discrimination on the basis of disability.

It aims to inspire health and social care organisations and practitioners to embrace the values and principles of the Convention and incorporate it into policy, procedure and practice.
“The HSE welcomes the move from a protectionist perspective to a rights based approach in relation to the matter of intellectual disability and sexual consent as outlined in the LRC consultation paper. It commends the recommendations which support the rights of people with disabilities to live fulfilled lives, including sexual lives, by self determination, whilst giving adequate attention to the issue of the appropriate protection from potential and actual abuse.”

The Model identifies what is required to build capacity:

- A knowledge of a human rights based approach – particularly application to practice.
- A knowledge of models of disability.
- A knowledge of approaches to capacity.
- Strategies for building capacity at an organisational, individual and at societal level.
- A knowledge of the law.
- A recognition of the part power plays with regard to consent.
Case Study

*NHS Trust v DE* [2013] EWHC 2562
E.N.A.B.L.E

Equality & Non Discrimination
THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

ACCESSIBILITY

ARTICLE 16: FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE

INDEPENDENCE OF PERSONS

ARTICLE 21: FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

FULL AND EFFECTIVE PARTICIPATION

ARTICLE 28: ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION

FULL INCLUSION IN SOCIETY

ARTICLE 19: LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

ARTICLE 27: WORK AND EMPLOYMENT

EQUALITY OF OPPORTUNITY

ARTICLE 30: PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORT

RESPECT FOR INHERENT DIGNITY

EQUALITY BETWEEN MEN AND WOMEN

ARTICLE 23: RESPECT FOR HOME AND THE FAMILY

NON-Discrimination

NOTHING ABOUT US, WITHOUT US!

USICD is a non-profit membership organization that works to catalyze the energy, expertise and resources of the US disability community and US government to help improve the lives and circumstances of people with disabilities worldwide. www.usicd.org
UNCRPD

• Adopted by the United Nations General Assembly - 13 December 2006.


• The Convention sets out the legal obligations on States to promote and protect the rights of persons with disabilities.
The Convention marks a ‘paradigm shift’ in attitudes and approaches to persons with disabilities.
The Purpose of the Convention.

The purpose of the Convention is to **promote, protect and ensure the full and equal enjoyment of all human rights** and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
Equality and Non-Discrimination

The two pillars of the Convention.

On an ‘equal basis with others’ is mentioned no less than 35 times.
Discrimination on the basis of disability is defined in Article 2 as “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of reasonable accommodation.
<table>
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<tr>
<th>Structures within Organisations / Society that can Discriminate and cause barriers to equality</th>
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<td>Attitude of those in a supporting role to autonomy and sexuality.</td>
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Substantive Equality and Reasonable Accommodation

A substantive equality measure and a key concept for the achievement of non-discrimination is reasonable accommodation.

Reasonable accommodation is defined as ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’
Reasonable Accommodation Measures

- Relationship and sexuality education – accessible format
- Accessible information regarding contraception
- Disability liaison officer at family planning clinics
- Participation in research in which people with disabilities can express their view.
- Opportunities to meet new people
ALL HUMAN BEINGS ARE EQUALS IN WORTH AND DIGNITY
What does the Convention aim to do with regard to sexuality / relationships.

It recognizes that people with disabilities may be subject to discrimination based on disability. For example, people with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex.

What does the Convention aim to do with regard to sexuality / relationships.

1. Promote sexual expression on an equal basis with other.

2. Ensure freedom from violence, exploitation and abuse is a vital aspect of our criminal law.

Case Study Prompts:

1. Reflect on the concept of equality and non-discrimination. How does knowledge of this concept build decision making capacity with regard to Daniel and Pauline’s situation.

2. Can you identify any potential practices, policies or attitudes that could possibly arise in this scenario that might constitute discrimination.

3. Outline how Daniel and Pauline could be offered reasonable accommodation measures to support them to make informed decisions.
E.N.A.B.L.E.

Ability
Traditional Approaches to Disability

Disability is viewed as a medical condition that requires fixing.

It is viewed as contained in the body of the person with a disability.

The person with a disability is in turn perceived as a passive recipient of medical care resulting in the marginalisation and objectification of that person.
It may be accepted that disability may be a long-term condition not amenable to medical treatment.

The person is considered incapable of living their own life and making decisions.

Barriers which exist in the environment are not identified and therefore are not removed.
The Convention characterises disability in terms of the relationship between the individual and society, and in particular the barriers society makes which excludes the person with disabilities. As such it is not for the individual to be cured of his or her disability .....it is instead for society to adapt to the needs of people with disabilities so that those people might maximise their participation in society as a whole.

(Peter Bartlett)
What are the Actions for Change to promote ability?
Ratification
Understanding
Effective Implementation
Monitoring
Case Study Prompts:

Describe how a particular model of disability might effect Daniel and Pauline’s situation.
E.N.A.B.L.E.

Building Legal Capacity
What is meant by the term legal capacity?

What are the approaches to legal capacity?

Building decision making skills
Legal Capacity / Mental Capacity

Mental Capacity – The decision making skills a person possesses.

Legal Capacity – The power to act within the law and make legally binding decisions and have those decisions respected and acted upon.
Legal Capacity

Health Care Decisions

Gain employment
Open a bank account
Take out a mortgage
Enter a tenancy agreement

Make a transaction in a shop
To Vote
Sign a contract
Access to justice
Consent to a sexual relationship
Approaches to Capacity

- Status Approach
- Outcome Approach
- Functional Approach
- Article 12 CRPD
Article 12 CRPD – Equal Recognition Before the law.

I HAVE THE RIGHT

TO ENJOY LEGAL CAPACITY ON AN EQUAL BASIS WITH OTHERS IN ALL ASPECTS OF MY LIFE, AND IF NEEDED, HAVE ACCESS TO SUPPORT TO EXERCISE MY LEGAL CAPACITY.
A new formula for legal capacity by Michael Bach.

- Individual will and preferences
- Unique decision-making abilities
- Supports
- Accommodation
- Equal legal recognition

Capability to make decisions
1. Organisational Capacity Building Strategies

2. Individual Capacity Building Strategies

3. Building Capacity in society
Organisational Capacity Building Strategies

The values and principles of the Convention and the Assisted Decision Making (Capacity) Act should infuse and permeate the entire organisation – Implementation Plan

A well resourced, active and accessible human rights review committee.

Resident and Staff training and education in the Convention and Act.
Internal inspection and monitoring of capacity building and capacity assessment.

Complaints procedure is active and accessible to all residents.

Advocacy groups are active and empowered by the organisation.

Residents sit on committees in a meaningful way.

Regulation is embraced and recognised as an opportunity and not seen as a threat.
Person Centred Planning is active.

Residents meetings happen and are effective.

Speak up councils.

Advocacy groups.

Relationship Sexuality Policy is active.

Independent Advocacy Service is accessible.

Accessible Information / Reasonable Accommodation.
Individual Strategies for Building Decision Making Capacity

- Decision making ability is no different than any other function that may be effected due to a condition such as a disability.

- What is our normal response as practitioners to skills teaching?

- We break down tasks, we sequence them give Information to the person, their families, carers.
Through practice and experience skills are required confidence builds and tasks become more natural. Decision making should be approached in the same manner.

The process builds on strengths and can be described as capacity building - a term that takes on added significance when the capacity that develops is decision making capacity.
A third party cannot give consent to enter a sexual relationship.

However decision making capacity can be built upon

We need to examine the criteria that defines consent and build knowledge and skills in those areas.
The HSE welcomes the strong references to education as an essential support to the exercise of consent to sexual relationships and to aid determinations as to the person’s capacity to give such consent.

Capacity to consent requires an awareness of the act of sex and the risks involved regarding sexually transmitted infections (STI’s) and pregnancy, information on contraception, emotions, and relationships.

The HSE notes, with interest the UK court (2011, High Court decision, D Borough Council v AB) concluded that sex education was a necessary precursor to assisting a man with Intellectual Disability in making a decision with regard to consenting to sexual intimacy.
Each person’s human need for intimacy is acknowledged.

Each person is supported on an individual basis, and in a sensitive and appropriate ways, to develop and maintain intimate relationships with others in accordance with their wishes and preferences and in adherence with current legislation.

The organisation’s policy on sexuality and Intimate relationships is available in the designated centre and produced in a more accessible format for residents as required.
There is a record that all staff have been inducted/introduced to the policy and have read and understand it.

A Personal Centred Plan interview has been completed in the last 12 months which has explored how the person defines the outcomes.

People have intimate relationships.

People have privacy.
Each resident’s personal plan has a section which describes the individualised supports required and provided in the area of developing and maintaining Intimate relationships.

There is evidence that residents have had the opportunity to participate in sex education, delivered in a format tailored to their learning and communication styles.

A sex education programme is informed by an assessment of need. The programme is comprehensive and on-going.
Sex education should consist of formal classes driven by an assessment of need with a specific curriculum.

Continuous support sessions

Informal day to day interaction guided by the Plissit Model

Education for family members.
Resident’s privacy is observed being respected – e.g. staff do not enter residents’ bedrooms, listen in on private conversations, or go through their personal belongings without their permission.

Permission giving’ in respect of relationships is evident in the environment i.e. resources are available, phone numbers of local sexual health centres etc.
Health and Safety

The person is supported to address their psychological and sexual health.

When considering a sexual relationship the person should be supported to enjoy a healthy relationship and be educated about sexual responsibility and their own personal safety. The person should be supported to avail of all sexual health services in the community.
An exploration of beliefs and values / will and preference.
Safeguarding from abuse should form a robust part of any programme addressing matters relating to sexuality and relationships.

The person should also be supported to consider is the relationship that they are considering healthy and free from any abuse. The individual should receive ongoing education on all aspects of abuse. If a staff member suspects that the individual is at risk from abuse within this relationship they should discuss their concerns with the individual and the supporting team.

Education for staff and family in safeguarding from abuse.
Building Capacity in Society

Forum for people with disabilities to self advocate e.g. “Someone to love”

The power of story telling

Education / Conferences

Family and caregiver education.

HSE propose a communication and information campaign to raise awareness throughout society about the proposed changes to legislation and the potential impact this will have on the rights of people with disabilities.
Recommendations included a reference to the drawing up of a code of practice to cover various aspects not covered in the actual legislation, the process of setting up the group to carry out this function, gathering submissions from stakeholders and launching the code would provide a useful educative vehicle.

The Department of Health has also indicated its interest in developing a national sexual health policy to specifically name sex education for adults at risk, their families and care givers and of the wider community, as a key priority;

Case Study Prompts:

If those who support Daniel operate under the status approach to legal capacity what effect will this have on his life?

How can Daniel’s capacity to make an informed decision about whether to enter a sexual relationship be built upon?

When considering the functional assessment what should be to the fore front of your mind?
How does law influence decision making?
General Information

A sexual relationships is lawful as long as the relationship is a consenting one and the parties have the capacity to engage in that relationship.

The age of consent to sex in Ireland as stated in the Criminal Law (Sexual Offences) Act 2006 is 17.
Let's Look Next At:

Section 5 the Criminal Law Sexual Offences Act 1993

The UN Convention on the Rights of Persons with Disabilities

Criminal Law (Sexual Offences) Bill 2015
Let’s bear this question in mind:

What are, or what should be, the markers of capacity to consent? In particular, what facts should a person know if they are to be deemed capable of giving consent to a sexual act?
Section 5 Criminal Law Sexual Offences Act 1993
Section 5 Criminal Law Sexual Offences Act 1993

Section 5 stipulates that a person who attempts to have sexual intercourse or ‘commit an act of buggery’ with a person who is mentally impaired shall be guilty of an offence.

This is a strict liability offence, which means that consent is not a defence.
There is no criminal offence, however, if the parties are married to each other, or if the victim is proven to be capable of living independently and protecting him or herself against abuse.

This law discriminatorily criminalizes sexual activity of people with mental impairments before marriage. It also requires proof that a person with mental impairment is able to live independently and protect him or herself from abuse before engaging in sexual activity.
What Impact has the law had?

This law discriminatorily criminalizes sexual activity of people with mental impairments before marriage. It also requires proof that a person with mental impairment is able to live independently and protect him or herself from abuse before engaging in sexual activity.
What Impact has the law had?

It does not recognize that people with mental impairment can engage in consensual sexual activity.

The “status” approach is evident in section 5 of the 1993 Act because, rather than determining capacity to consent by reference to whether a specific individual understands the nature and consequences of the sexual act, section 5 bypasses this completely. Section 5 provides, simply, that an offence is committed where sexual intercourse occurs with any “person who is mentally impaired.”
It does not recognize that people with intellectual or learning disabilities and other forms of mental impairment participate in loving sexual relationships.

It also does not recognize that they can refuse sexual encounters.

In addition, since it rarely has been successfully prosecuted, and only applies to sexual intercourse and buggery, it is inadequate in protecting people with disabilities against the various forms of sexual abuse which exist.
“We don’t want laws that are about testing us. We want proper sex education. Then we can make our own choices. We don’t want special laws for people with extra support needs either. The new law should be disability neutral. It should apply to everyone. We want you to listen to our opinions. We want you to take them seriously.”

Connect People Network – Self Advocacy Group.
What does the Convention aim to do

1. Promote sexual expression on an equal basis with other.

1. Ensure freedom from violence, exploitation and abuse is a vital aspect of the criminal law.
Article 12 establishes that all people with disabilities must be recognised as having legal capacity to consent to sexual relations on an equal basis with others.

This precludes the use of a separate standard or test of capacity for people with disabilities, for assessing consent to sexual relations.

There instead should be a general test for consent as there is within the general population – a requirement of disability neutral criteria.
What would a Convention Compliant Law look like?

General test of consent which can take into account and individual’s decision-making capability, and introducing a general offence of abuse of position or power, which applies to all adults who could be in a vulnerable situation, including people with disabilities.
Have we examples of such laws?

The Norwegian Penal Code, Ch. 19 Sexual Offences § 193

The Criminal Law (Sexual Offences) (Amendment) Bill 2014

Law Reform Commission recommended in its report on Rape and Allied Offence suggested that legislation should be enacted which defines consent. This definition if applied to all people would be CRPD compliant.
The Criminal Law (Sexual Offences) (Amendment) Bill 2014

Private Members Bill - Senator Catherine Zappone.
The first step in establishing the existence of consent is to ascertain whether the parties had agreed to engage in the specific act.

In ascertaining whether the parties had agreed to engage in the specific act, the court must look at two things, firstly, the communications which took place immediately before the sexual act, and secondly, it must be shown that at that time, each person understood the nature of the act which was about to be engaged in.

The person is required to understand the physical nature of the act and not the physiological consequences.
For valid consent to sex, [an individual] ... must know that sex, especially when initiated by a more powerful person, is not required and compulsory.

People must have sufficient communication skills to be able to make their choice (to engage in sexual activity or not) known to the other party. This means that either verbally or through an alternative communication system known to both parties they must be able to give/deny/withdraw consent at any stage in the activity. Silence or non-communication must not be interpreted as consent.
There needs to be a reasonable degree of equality between the parties, so that both parties have sufficient power to make the choice to engage or not engage in sex, without fear of adverse consequences.
Article 12(3) requires the creation of a system of supports for the exercise of legal capacity. This includes not only the provision of supports in decision making, but also the provision of supports aimed at augmenting decision-making capabilities to lead to self-determination. While support at the actual moment of decision-making in sexual relations is impractical and would likely be a violation of privacy rights, on-going support in how to make decisions of a sexual nature can allow an individual to be prepared to make informed decisions regarding consent to sexual relations.
The bill introduces an “offence of abuse of position of dependence and trust” legislation prohibiting or criminalising exploitation, violence and abuse is one element of the necessary protection.

The implementation an effective adult safeguarding policy and programmes is the key to realising this right for people with disabilities, as this will lead to abuse being ‘identified, investigated, and, where appropriate, prosecuted.

access to justice and redress for survivors of abuse, and independent monitoring to ensure compliance with the relevant standards and safeguards.

The implementation of a national adult protection programme which could take positive steps to prevent abuse, exploitation or violence against adults would also be a core element of any holistic approach to ensure informed consent.
Article 17: The Right to Physical and Mental Integrity

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

The right to integrity includes rights to engage in sexual activity and reproductive rights.

Persons with disabilities should be entitled to not only the same level of protection but also to the same level of freedom as persons without disabilities in the vindication of their rights to sexual expression.

Article 19: The Right to Live in the Community

The right to develop intimate relationships and to sexual expression can be considered a key element of the right to independent living.

The text of Article 19 reinforces the commitment made in Article 12 to respect the choices of people with disabilities, including ‘where and with whom to live’ – an issue closely connected with personal relationships.
Articles 22 & 23

The right to privacy and to respect for home and family life, protected in Articles 22 and 23 of the CRPD.
These provisions support the contention that people with disabilities have equal rights to relationships as do others who have reached the age of consent. The Convention prohibits any ‘arbitrary or unlawful interference’ with privacy, including privacy in connection with sexual relationships, and arguably, the existence of a specific offence which criminalises sexual activity engaged in by people with disabilities, violates the right to privacy which people with disabilities should enjoy. Similarly, such an offence constitutes discrimination regarding relationships entered into by people with disabilities, which is specifically prohibited in Article 23.
The Criminal Law (Sexual Offences) Bill 2015

Part 3

Sexual Act with Protected Persons.
The new Bill, if passed, would create the offence of a sexual act with a protected person.

Protected persons will not have capacity to consent to sexual acts if he or she is, by reason of a mental or intellectual disability or a mental illness, incapable of—

Understanding the nature, or the reasonably foreseeable consequences, of that act,

Evaluating relevant information for the purposes of deciding whether or not to engage in that act, or

Communicating his or her consent to that act by speech, sign language or otherwise.
This Bill has the effect that relationships between adults with an intellectual disability would be lawful where consent is present.
To identify those who require protection, a functional test as to the capacity of a person with a mental or intellectual disability or a mental illness has been adopted.

This provision seeks to attain the necessary balance and to ensure that appropriate protection is available to those who need it while respecting full participation in society of persons with disabilities.
“The provision in this Bill adopts a very different approach and looks to the capacity of the person to consent. It does not presume that the existence of a disability implies a lack of capacity to consent”.

Minister Francis Fitzgerald http://oireachtasdebates.oireachtas.ie/debates
Case Study Prompts:

Give one possible effect each of the following laws or proposed law could have for Daniel and Pauline.

The Criminal Law Sexual Offences Act 1993
The Criminal Law (Sexual Offences) (Amendment Bill ) 2014
The Criminal Law (Sexual Offences) Bill 2015.
Equal Status Approach
An Acknowledgement of the power dynamic

Is there an underlying power dynamic within disability services?

Are there hidden and invisible aspects of power?

What evidence is their of ‘real’ service user involvement / leading of services?

Or is the ‘service user involvement’ tokenistic – a way of masking power imbalances.

Without addressing power imbalances service-user involvement may simply be a way for decision-makers to legitimize their decisions.
A priority in services should be the development of a ‘Strategic Model of Power for Service User Involvement’.

Power can have three forms:

Visible – determines the way decision making forums operate.

Hidden – Power which is held by powerful actors who influence what is put on the decision making table or more importantly not put in the decision making table.
Invisible - Significant problems and issues are not only kept from the decision-making table, but also from the minds and consciousness of the different players involved, even those directly affected by the problem.

(Gaventa 2006 A Three Dimensional Model of Power)

Dr Liz Brosnan Power and Participation: An Examination of the Dynamics of Mental Health Service-User Involvement in Ireland
**Service user Involvement:**

Strategic Planning: shaping legislation, staff recruitment, delivering training to professionals and developing peer-support worker roles.

How the service is delivered: This may involve attending committees that are concerned with operational issues, developing local policies and practices that are more responsive to service users’ needs. It may also involve monitoring and evaluation of services, and user involvement in research.
Individual decision-making: in relation to a person’s supports, the choices they can exercise about treatments, about their individual care plans.

Dr Liz Brosnan Power and Participation: An Examination of the Dynamics of Mental Health Service-User Involvement in Ireland
Case Study Prompts

Explore the power dynamics that may exist with regard to Pauline and Daniel and the nature of the support they receive.
Thank You