



NATIONAL ADVOCACY SERVICE
FOR PEOPLE WITH DISABILITIES

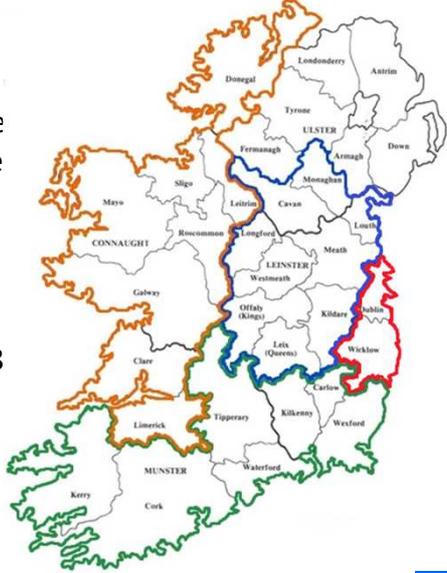
LEGAL CAPACITY CONFERENCE
UCC AND IMHLA
9TH APRIL 2016
By Louise Loughlin
National Manager

WHAT IS THE NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES ?



NATIONAL ADVOCACY SERVICE
FOR PEOPLE WITH DISABILITIES

- Launched in March 2011
- Comhairle Act 2000 and The Citizens Information Act 2007 gave CIB a statutory function to provide advocacy to people with disabilities;
- National Manager and 4 regional teams, 4 regional managers, 7 senior advocates, 5 admins and 28 advocates;
- Based on the principles of empowerment, inclusion, autonomy and citizenship.



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DISABILITY IN IRELAND



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- Currently there are 600,000 people who are defined as having a disability in Ireland (CSO, 2012);
- Probably figure a lot higher (undiagnosed/misdiagnosed);
- International research studies highlight the impact of disability on a person's sense of self and how this can have major impacts on their engagement with professionals (Nettleton, 2005; 2013).

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HOW WE COMMUNICATE



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FOR PEOPLE WITH
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- Studies show that people with a disability experience greater communication barriers by 66 % (Farrelly, 2012);

Professional services need to make a shift to reach out to people with 'different communication';
- 70% of Human Communication is Non-verbal;
- Often acceptance of communication limitations restricts a person's right to make decisions.
- <http://www.gov.scot/Resource/Doc/210958/0055759.pdf>

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WHY IS THERE A NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES ?



NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- Because sometimes people with disabilities are not listened to or given the chance to make their own choices.
- People with disabilities are often treated differently from non disabled people.
- Nearly everyone agrees that we should all be treated the same and have the same chances and choice in life.
- NAS aims to ensure that people with disabilities have those chances and choices.



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Why Professional Advocacy ?



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Everyone should be able to:

 <p>make choices</p>	 <p>exercise their rights</p>
 <p>be independent</p>	 <p>be part of their community</p>

People who have disabilities often experience difficulties in asserting their views and/or securing their rights and entitlements. This can lead to people have limited choices and little control over their lives.

Professional Advocacy can help address this.

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WHO IS NAS FOR ?



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FOR PEOPLE WITH
DISABILITIES

The main focus of the service are the people in the most vulnerable situations, including those who are;

- isolated in the community
- residing in inappropriate accommodation
- unconnected to services
- and those with communication differences who may find it difficult to represent themselves.

NAS uses Access and Eligibility Criteria to determine when to open a case.

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LEGAL FRAMEWORK



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FOR PEOPLE WITH
DISABILITIES

NAS operates in a framework of existing Irish and other law which is outlined below.

We use these laws to inform and guide our practice, and as tools for resolution of client issues by way of representation and negotiation.

- Disability Act 2005 (assessment of need – currently for children only);
- Citizens Information Act 2007 (onus on CIB to support the provision of advocacy for people with disabilities);
- Assisted Decision Making (Capacity) Act 2015;
- European Convention of Human Rights Act 2003;
- UN Convention on the Rights of People with Disabilities (signed by the ROI but not yet ratified)

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LEGAL FRAMEWORK CONT.



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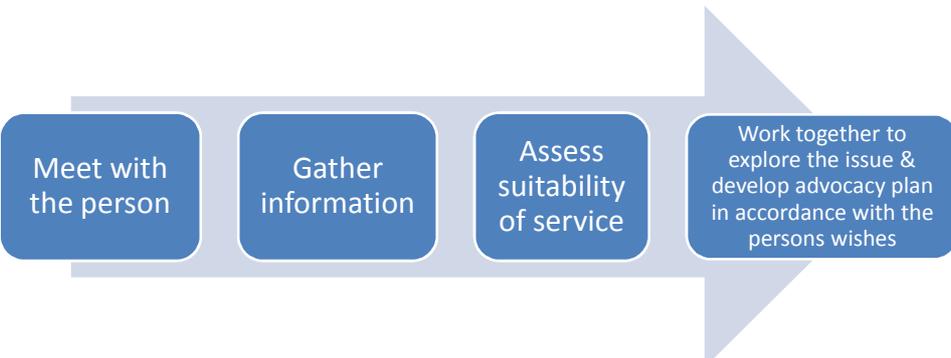
- We also look to Government policy including:-
 - National Disability Strategy;
 - Vision for Change (2006);
 - Time to move on – Congregated Settings (2011);
 - Vfm & Policy Review of Disability Services in Ireland (2012);
 - HIQA Standards;
 - MHC Standards

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WHEN AN ENQUIRY IS RECEIVED BY NAS



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graph LR; A[Meet with the person] --> B[Gather information]; B --> C[Assess suitability of service]; C --> D[Work together to explore the issue & develop advocacy plan in accordance with the persons wishes];
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The role of the advocate is to get to know the person and support them to have their wishes and preferences at the centre of the decision making process.



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WHEN A REFERRAL IS RECEIVED CONT.

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In a case where the client is not in a position to articulate their will or preferences the advocate uses 4 internationally recognised approaches to try to ascertain the person’s will and preference. The advocate examines the options available, asking questions on the person’s behalf and, and examines how the course of action will impact on the person’s quality of life.

Approaches when working with a person with communication differences

PERSON CENTREDNESS

WITNESS OBSERVER

RIGHTS BASED APPROACH

ORDINARY LIFE PRINCIPLES
Eight Quality of Life Domains

Gathering Information

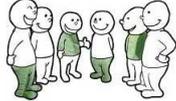
- From the person
- Policy documents
- Person Centred Plans
- Various professionals
- Significant people in the persons life e.g. family

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Eight Quality of Life Domains (ASIST Advocacy Services in Staffordshire)			
DOMAIN	FOCUS	AVOIDANCE	SAMPLE QUESTIONS: HOW WILL THE PROPOSAL:
Competence To have a level of skill to be as independent as possible	Learning and developing skills which lead to a greater independence or allow minimal support, dependence and inactivity	Having to rely on others, not taking risks or allowing people to do things by themselves	<ul style="list-style-type: none"> Promote the person’s independence? Support them to develop new skills and maintain existing ones? Manage risk?
Community Presence Having a sense of belonging to a local area by means of access and use	Encourage a high frequency of use and involvement in local public facilities and amenities	Using segregated services or not using local facilities enough	<ul style="list-style-type: none"> Promote the person’s presence in the local community? Affect existing opportunities? Provide new opportunities? Reduce social isolation?
Continuity Having a past, present and future with key people and events in your life	Meaningful relationships which last over time planning out your life’s hopes and ambitions	Stagnation and loss no past and no future, only the present	<ul style="list-style-type: none"> Help the person maintain links with their past? Address their hopes and ambitions for the future? Maintain continuity in their life?
Choice and Influence Being able to determine the course of events, looking at situations from your perspective	Self-determination, self-advocacy, asking your own decisions and choices because you want to	Domination over protection, no involvement in the way your life is directed	<ul style="list-style-type: none"> Offer options? Involve the person in decision making? Take their wishes into account?
Individuality A unique person in your own right	Individual needs and wishes, support that is responsive to individual demands	Grouping and labelling	<ul style="list-style-type: none"> Address the person’s preferences Promote individuality? Offer opportunities to express preferences?
Status and Respect Having value in the eyes of others	Raising others’ expectations and the removal of social stigma and prejudice	Not placing value on a person by degrading them by age, culture or activity	<ul style="list-style-type: none"> Promote self-respect and the respect of others? Reduce prejudice and social stigma? Value the person in a way consistent with their age, gender, cultural needs etc?
Partnerships and Relationships Having meaningful interaction with other people	Valuing interaction and friendship, promoting social networks	Having no one in your life who is important, only associating with other devalued people	<ul style="list-style-type: none"> Provide opportunities for interaction with others? Promote development and maintenance of positive relationships?
Well Being Having a state of physical, psychological and social health	To maintain a balance between all health needs, to promote health	Accepting illness and disability, not securing appropriate health support and treatments	<ul style="list-style-type: none"> Promote and maintain good health? Recognise and address health issues?

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WHAT THINGS CAN WE HELP WITH ?  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

<p>Where to live</p> <ul style="list-style-type: none"> • Who to live with • What kind of place do I want to live in 	<p>What to do during the day</p> <ul style="list-style-type: none"> • Working • Training • Learning 
<p>What to do in the evening</p> <ul style="list-style-type: none"> • Sports • Hobbies • Socialising 	<p>Transport</p> <ul style="list-style-type: none"> • How can I get around 
<p>Quality of life</p> <ul style="list-style-type: none"> • Loneliness • Fear of speaking up • Equal treatment "mainstreaming" – use services like everyone else • Services – mental health, physio, social work, housing, county council 	<p>Money</p> <ul style="list-style-type: none"> • How much do I have • Who makes decisions about my money • How can I make decisions myself 
<p>Medical</p> <ul style="list-style-type: none"> • Why do I have to see doctors • Why do I take medicines • How can I find out more • What choice do I have 	

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WHAT TYPE OF THINGS DO WE DO ?  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

We might:-

- Spend time with the person listening to them
- Find out who is involved in decision making in the person's life;
- Find out who is in the person's life – family and friends and talk to them
- Find out what the person's financial situation is
- Meet with the person who can make decisions – HSE, social worker, manager, doctor
- Support the client to find out more about what they want to do
- What else will the client need to help achieve their goal?

We always work with you the person, we might listen to other people, but we always support you in what you want to do.

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NAS CASE EXAMPLE:



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A CLIENT WITH AN ABI SEEKS THE ASSISTANCE OF THE NAS TO GET DISCHARGED FROM WARDSHIP



- The client contacted the advocate about discharge from wardship. The lady had sustained a brain injury following a RTA several years before.
- The client and advocate developed an advocacy plan.
- Actions undertaken by the client and advocate:
 - ✓ Accompanied client to solicitor
 - ✓ Assisted client to explore the option of legal aid
 - ✓ Assisted client to liaise with Ward of Court office by email, letter and phone
 - ✓ Assisted client to liaise with medical professionals and to document their life story for the independent medical assessor
 - ✓ Assisted client to identify appropriate community supports
 - ✓ Provided support and encouragement as this process had been under taken in the past
 - ✓ Client was discharged from wardship

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ADVOCACY AND THE ADM



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- s8.(2) It shall be presumed that a relevant person who falls within paragraph(a) of the definition of “relevant person” in *section 2(1) has capacity* in respect of the matter concerned unless the contrary is shown in accordance with the provisions of this Act.

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ADVOCACY AND THE ADM  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- NAS works from the premise that all persons who use our service have capacity, but that they may need some support to express their will and preference;
- It is for us to discern that will and preference and to support the communication of that will and preference to other parties;
- It can be seen therefore that NAS has already incorporated the s8 principles into practice;

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ADVOCACY AND THE ADM  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- The implementation of the ADM is likely to be challenging for many organisations and professions including advocacy;
- The Act has not given citizens a right to advocacy;
- Although advocacy is recognised in the HIQA standards for residential services for people with disabilities, and the Mental Health Commission Code of Practice;

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ADVOCACY AND THE ADM  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- Advocacy is often not fully supported as many services still operate on a ‘best interests’ model and recognise family members as ‘next of kin’ and bestow decision making authority upon them;
- We have a *de facto* substitute decision making regime;
- Ireland requires a cultural shift towards supported decision making and there is an onus on us all to participate in and encourage that shift;

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ADVOCACY AND THE ADM  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

The ADM does make provision for a Code of Practice around advocacy:-

- S103(2) The Director (of the DSS) may—
 - (a) prepare and publish a code of practice,
 - (b) request another body to prepare a code of practice, or
 - (c) approve of a code of practice prepared by another body, whether or not pursuant to a request referred to in paragraph (b),
 - (x) the guidance of persons acting as advocates on behalf of relevant persons;

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ADVOCACY AND THE ADM  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- Decision making assistance agreement
- Co-decision making agreement
- Court appointed decision maker
- Expert reports
- Capacity assessments
- There is a role for advocacy in all of these areas for people with disabilities in the context of supporting individuals to have their voice heard

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ADVOCACY AND THE ADM  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- There is possibly scope for NAS to act as decision making assistants;
- However, this would possibly require a move away from advocacy as we currently practice as it is not 'pure advocacy';
- NAS would not act as co decision makers or court appointed decision makers as these are both forms of substituted decision making;
- Scope for a role in expert reports and capacity assessments in ensuring that the person is at the centre of these processes and that there is an understanding around the person's method of communication and to provide relevant contextual information;
- All of this requires additional resources and training

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HOW CAN ADVOCACY WORK WITH OTHER PROFESSIONS ?



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- If we all engage in the cultural shift we may move towards:-
 - ✓ Changing how we think about people who need support with decision making;
 - ✓ Recognition of the right of individual to make their own decisions;
 - ✓ Change how we take instructions;
 - ✓ Challenge our own assumptions about capacity.

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SCOTTISH EXPERIENCE OF NEW CAPACITY LEGISLATION



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- Outmoded system of curator bonis and curator ad litem; tutor dative and tutor-at-law for adults who were 'incapax' (judicial factors act 1849);
- Extremely complex court process;
- Appointments were usually solicitors or accountants;
- Approach was to preserve the estate and act in the best interests.

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SCOTTISH EXPERIENCE OF NEW CAPACITY LAWS  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- Old regime was overly restrictive
- Ignored the realities of everyday life
- Did not pull together all the different strands
- Overhauled by adults with incapacity (scotland) act 2000

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ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

An Act of the Scottish Parliament to make provision as to the property, financial affairs and personal welfare of adults who are incapable by reason of mental disorder or inability to communicate; and for connected purposes.

PART 1
General

1 General principles and fundamental definitions

- 1) The principles set out in subsections (2) to (4) shall be given effect to in relation to any intervention in the affairs of an adult under or in pursuance of this Act, including any order made in or for the purpose of any proceedings under this Act for or in connection with an adult.
- 2) **There shall be no intervention in the affairs of an adult unless the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention.**
- 3) Where it is determined that an intervention as mentioned in subsection (1) is to be made, such intervention shall be the **least restrictive option** in relation to the freedom of the adult, consistent with the purpose of the intervention. (4) In determining if an intervention is to be made and, if so, what intervention is to be made, account shall be taken of—
 - (a) **the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid** (whether of an interpretative nature or otherwise) appropriate to the adult;

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ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- Most applications direct to the OPG
inexpensive, reasonably accessible cf previous procedures;
- Access to advocacy built into processes
- LA available where financially eligible
- Intervention orders through local sheriff court
- Quick and considered judgements;
- Discharge of curator bonis through local sheriff court - quick and accessible

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ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- Established office of public guardian
- Introduced welfare powers of attorney
- Welfare guardians
- Financial guardians
- Intervention orders

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EXAMPLE



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FOR PEOPLE WITH DISABILITIES

- Young woman with very supportive family
- In RTA when aged 15
- ABI - frontal lobe - decision making affected, impulsive, disinhibited;
- Retired accountant appointed curator ad litem to manage insurance settlement
- By default exercised huge control over her life

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SCOTTISH GOVERNMENT CONSULTATION ON CAPACITY LEGISLATION

Consultation on the Scottish Law Commission Report on Adults with Incapacity https://consult.scotland.gov.uk/disclosure-scotland/vulnerable-groups/consult_view (closing date 31st March 2016)

- Deprivation of liberty
 - Hospital settings
 - Community settings
 - Degrees of deprivation of liberty
- Also currently consulting on the draft delivery plan 2016-2020 of the UNCRPD which includes the following commitment:
 - “We will consult on the Scottish Law commission’s review of the Adults with Incapacity Act in relation to its compliance with Article 5 of the ECoF HR, specifically in relation to Deprivation of Liberty and thereafter carry out a scoping exercise in relation to wider review of the Adults with Incapacity legislation”

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NATIONAL ADVOCACY SERVICE

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LAW SOCIETY OF SCOTLAND'S RESPONSE



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- Central to the Society's proposals is that the separate jurisdictions, currently fragmented across courts and tribunals, should be combined in a single tribunal structure, with specialist expertise and local accessibility across Scotland.
- "The Adults with Incapacity (Scotland) Act 2000 was world-leading in its time but it now it is in desperate need of updating to ensure people at risk are protected. There needs to be a massive and comprehensive review of all three areas of legislation, taking account of current UN and European human rights standards for people with intellectual disabilities." Adrian Ward, convener of the Law Society's Mental Health and Disability Committee, 4th April 2016

<http://www.lawscot.org.uk/news/2016/04/vulnerable-adult-protections-need-urgent-review/>

LESSONS FOR IRELAND



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DISABILITIES

- Ignore Deprivation of liberty at our peril
- Will not be UNCRPD compliant unless this is addressed
- Access issues for Legal Aid, local court access and user friendly systems are essential;

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CURRENT DEVELOPMENTS AND ADVOCACY  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- HIQA Portlaoise investigation recommended establishment of a Patient Advocacy Service;
- Outgoing Minister for Health made a commitment to establish same
- Joint Committee on Health and Children
 - “Report on the Role of Advocacy in Health and Social Care Services in Ireland” January 2016
<http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2015/JCHC-Report-on-Advocacy-190116-web.pdf>
 - “It is recommended that the national patient advocacy service help to co-ordinate advocacy services, and develop a Code of Practice for advocacy services in agreement with a range of national stakeholders. This would ensure that all professional and voluntary advocates operate to the same ethical and legal standards.”

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CONCLUSION  NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

- NAS welcomes the ADM;
- Some reservations about the emphasis on functional capacity;
- Change in culture required across health and social care and the legal professions;
- We all need to think about how we communicate and how we can go into the space with the person.

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A video of this talk is available. Follow the links at www.ucc.ie/law/docs/mentalhealth/conferences/capacity-2016.shtml