

Who makes decisions about my life?

Why Autism Strategies need to address the issue of legal capacity: substituted vs supported decision-making. What is the difference and Why does it matter?

Yo Dunn

Consult Yo Ltd.

autism@consultyo.com

notjustautism@consultyo.com



CONSULTYO LTD.

Structure

1. Why should legal capacity matter to autistic people, families and professionals?
2. The current situation around Europe
3. Autism strategies and legal capacity
4. Where do we go from here?
5. Discussion



1. Why should legal capacity matter to autistic people, families and professionals?



What is legal capacity? 4 of 24

- Adults have the right to make a wide range of legally significant decisions
- We can:
 - Sign a tenancy agreement or own property
 - Open a bank account, borrow money and use banking services
 - Buy goods and services including travelling freely
 - Sign an employment contract (be an employee or an employer) or own a business
 - Refuse medical treatment and care including medication and admission to hospital or a care home
 - Get married
 - Consent to sexual activity
 - Vote and stand for election to public office
 - Inherit money, goods and property
 - Control where and with whom we live; who we want to have relationships with; where we travel; how we spend our money; who can enter our homes and most aspects of our lives.



The difference between legal and mental capacity

Legal capacity

The **right** to make
legally binding
decisions

Mental capacity

The **ability** to make
decisions

Legal capacity ≠ Mental capacity

Legal capacity = fundamental rights and freedoms
that adults are entitled to

Legal capacity = recognition in law of adulthood
and the **right** to control one's own life



How does this affect Autistic people?

- In most countries there is a legal procedure where some or all of an individual's **legal capacity** can be taken away if they are believed to lack the **mental capacity** to make their own decisions
- → Someone else making decisions about the adult's life **instead of the adult** and loss of the legal right to choose differently
- Many Autistic people subject to these procedures



But ...

- Surely some people actually can't make decisions for themselves?
- Doesn't this approach protect Autistic adults who can't manage their own affairs from legal responsibilities they can't manage and may not want?
- Isn't this Protective? Safer? Kinder?
- Isn't this the best way to ensure family members can continue to help and support their loved ones into adult life?
- Isn't this the only way to give family members legal standing to help an Autistic adult manage their affairs?



Ways of helping with decision making

Substituted

Supported

Autistic adult as object

Autistic adult as subject

Guardianship model

- P may not even be informed of legal proceedings leading to being placed under guardianship
- P can be placed and subjected to treatment in institution without consent
- P loses right to appeal to a court
- Barred from voting, getting married
- Guardian controls whether P can work, have children, have relationships, sex, bedtime, food, drink etc.

Support model

- P can choose support network
- Supporters will help P to understand and make decisions
- If necessary, P can have a representative to act **as their agent on their behalf**
- P has full access to information and right to attend meetings
- P can live in community with choice of support
- P has right to vote, work, form relationships, have children and parent – with support if needed



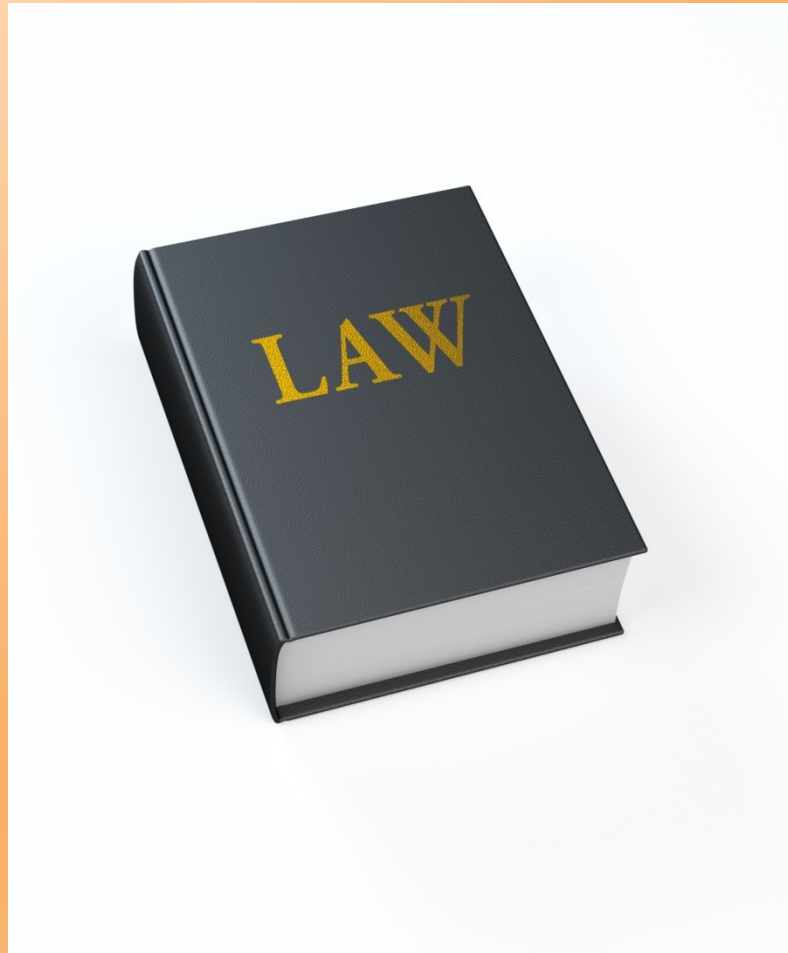
Does it matter?



“The right to legal capacity is one of the most invisible human rights issues in Europe today, and is also one of the most important” [\(Hammarberg, 2013\)](#)



2. The current situation around Europe



The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

- Sets a high standard: full equality. But, ethically, is a lesser goal really acceptable?
- Article 5 requires non-discrimination – a challenge to any diagnosis based element in decisions about legal capacity
- Article 12 requires equal recognition before the law and specifically legal capacity on an equal basis and support in exercising it



Substituted decision making systems which allow removal of all or virtually all legal decision making rights including right to vote and/or to appeal capacity decision to a court

- Albania
- Bosnia and Herzegovina
- Belarus
- Bulgaria*
- Croatia
- Estonia
- Hungary (law reform legislated but never brought into force)
- Italy
- Lithuania
- Luxembourg
- Macedonia
- Moldova*
- Norway
- Poland
- Portugal
- Romania
- Russia
- Serbia
- Slovakia
- Slovenia
- Switzerland (?)
- Ukraine

*Law reform under discussion



Substituted decision making systems 14 of 24

which allow retention of some legal rights including (at least) right to vote and to appeal capacity decision to a court

- Austria
- Belgium
- Czech Republic – includes some provision for supported decision making
- Denmark
- England & Wales
- Finland
- France
- Germany
- Greece
- Iceland
- Latvia
- Netherlands
- Northern Ireland
- Scotland
- Spain
- Sweden



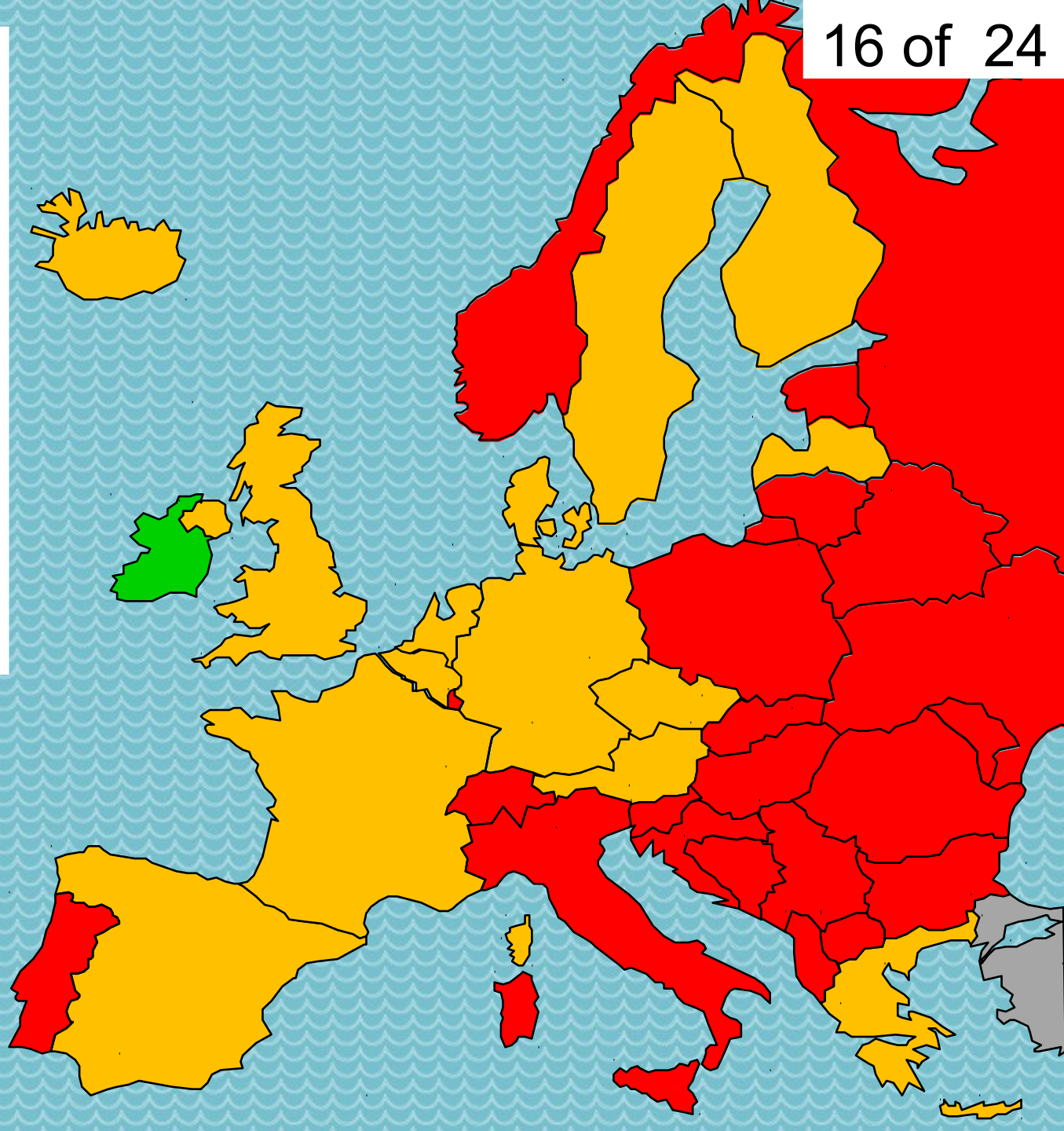
Full Supported decision making systems which do not remove legal capacity (UNCRPD compliant)

- Republic of Ireland (enacted 2015, expected to be brought into force late 2016)



Rough
categorisation
of legal
capacity laws
affecting
adults with
mental
disabilities
across Europe

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3. Autism strategies and legal capacity



England

- A passing mention of the Mental Capacity Act in a list of relevant policies and legislation
- Statutory Guidance 7.4

“It is important that those who support people with complex needs, whose behaviour may challenge or who may lack capacity should have a good understanding of supported decision-making; understand the principle that people should not be treated as lacking capacity simply because they make an unwise decision; should consider their wishes and feelings”

- And that's all!



Scotland

- Brief reference to the Adults with Incapacity (Scotland) Act 2000 in the context of its use to 'protect' adults in safeguarding situations
- A longer mention in the Learning Disabilities Strategy ('The keys to life') but only a page describing the Guardianship procedure under the Adults with Incapacity (Scotland) Act 2000 – no critical evaluation nor proposals for any change



European Union

- EU Disability Strategy 2010-2020 Section 3 Equality
“EU action will support and supplement national policies and programmes to promote equality, for instance by promoting the conformity of Member State legislation on legal capacity with the UN Convention.”
- But that’s the only mention. The issue is ignored in all the other areas of the strategy – even though all are affected by the issue
- No mention in the European Parliament’s Written Declaration on Autism
- Autism-Europe’s manifesto – just general call for full compliance with UNCRPD

The UNCRPD on the European Union

“The Committee notes with deep concern that across the European Union, the full legal capacity of a large number of persons with disabilities is restricted”

[Concluding observations on the initial report of the European Union, UN Committee on the Rights of Persons with Disabilities 2015](#)



4. Where do we go from here?

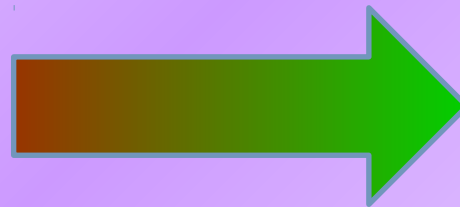
Seek Law Reform

- To restore full legal capacity to Autistic (and other disabled) adults on an equal basis with others (distinguishing between mental capacity and legal capacity)
- To replace substituted decision making systems with supported decision making systems in which adults retain full rights and are able to choose trusted people to support them in exercising those rights

4. Where do we go from here?

Seek shift in practice and culture

Paternalism



Support to
exercise
autonomy



5. Discussion

“Without legal capacity, we are nonpersons in the eyes of the law and our decisions have no legal force”

Thomas Hammarberg (2008)

Some practical issues:

- Lack of autism specific data
- Should we be prioritising particular countries as the most urgent targets for campaigning?
- How does this relate to campaigning around closing institutions, protection from abuse and Deprivation of Liberty?