Assisted Decision-Making (Capacity) Act 2015: how will it work?

16 May 2017

What this Note does

This short *Note* looks at the reforming legislation that is the *Assisted Decision- Making* (*Capacity*) *Act 2015*. The *Note* looks at what is contained in the Act and how the legislation will work in a health and social care context as well as more broadly. The *Note* is structured as follows:

- Overview
- Using performance information to scrutinise the Act
- Implications of the Act in health and social care
- Ensuring compliance with the legislation
- Significant amendments made to the Bill by the Oireachtas
- Stakeholder recommendations not reflected in the Act

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Overview

The overall objective of the *Assisted Decision-Making (Capacity) Act 2015* (the Act) is to put in place a modern legislative framework to support those with capacity difficulties and which complies with the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

S.3 of the Act states that a person's capacity will:

"...be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time."

The Act is a reforming piece of legislation which abolishes the previous Wards of Court system provided for by the *Lunacy Regulation (Ireland) Act, 1871*. Essentially this means that those with difficulty making decisions about their finances, healthcare, living arrangements etc. will be helped, where possible, to make these decisions for themselves. Where this is not possible, a representative will be appointed by the Circuit Court to make certain decisions. This role, as well as other decision-making roles provided by the Act, will be supervised by the new Decision Support Service (DSS), to be based in the Mental Health Commission. The DSS has not been established at present. The Minister of State at the Department of Health, Mr. Finian McGrath, T.D. told the Dáil on 28 March 2017 that:¹

"A high-level Steering Group comprised of senior officials from the Department of Justice & Equality, the Department of Health and the Mental Health Commission is overseeing the establishment and commissioning of the Decision Support Service and this work is ongoing."

Information relating to the status of the DSS is available here.

<u>Inclusion Ireland</u> state that the *Assisted Decision-making Capacity Act 2015* is a "seismic cultural shift" towards a rights-based approach of choice, control and consent.²

The Act is intended, broadly, for three categories of people:

- those with intellectual disabilities;
- older people with degenerative cognitive conditions; and
- people with mental health issues.

Box 1: intellectual disability, mental health and brain injury

- Since 1974 the number of people with an **intellectual disability** has increased by 46%.³ There were 28,108 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2015 (a prevalence rate of 6.13 per 1,000 population).⁴
- 100,000 adults have a long-standing **mental health condition** (National Disability Survey 2006).
- While there are no official statistics for the number of people living in Ireland with a brain injury, it is estimated that between 9,000 and 11,000 people sustain a traumatic brain injury every year in Ireland with a further 7,000 being diagnosed with a stroke.⁵

Cultural shift towards a rights-based approach

The new legislation is a departure from the Wards of Court system, which took a paternalistic approach to capacity issues, whereby a person who was unable to make decisions in one area of their life (e.g. finances) was denied the right to make other significant decisions. The problem with such a paternalistic approach is described by the United Nations in the following paragraph:⁶

"The concept of guardianship is frequently used improperly to deprive individuals with an intellectual or psychiatric disability of their legal capacity without any form of procedural safeguards. Thus, persons are deprived of their right to make some of the most important and basic decisions about their life..."

The Assisted Decision-Making (Capacity) Act 2015 takes a more flexible approach, looking at each decision at a point in time and making the assumption that the person has the capacity to make that decision. Where they are unable to make decisions on their own, the Act provides for the appointment of decision-makers (on a graduated scale, in accordance with the level of need), who can help them do so. At all times, where possible, the person's will and preferences must be taken into account.

Gerard Quinn from the <u>Centre for Disability Law & Policy</u> NUIG describes the "paradigm shift" as a result of Article 12 of the UN Convention on the Rights of Persons with Disabilities:⁷

"By the paradigm shift I mean three things. I mean the shift way from treating people with disabilities as 'objects' to be managed or cared for to honouring and respecting them as 'subjects'. I mean restoring voice, power and authority to the self over him or her self. And I mean respecting this power and authority by forging pathways to independent living and participation."

The new capacity legislation is an important step in Ireland's ratification of the UN Convention on the Rights of People with Disabilities (UNCRPD), which was signed by Ireland on March 30th 2007. Another important piece of legislation, in this regard, is the *Disability (Miscellaneous Provisions) Bill 2016*, which amends a number of Acts in order to progress Ireland's ratification of the UNCRPD. The Bill completed second stage in Dáil Éireann and was referred to select Committee on 23 February 2017.⁸

The Department states that the provisions of the *Assisted Decision-Making (Capacity) Act* 2015 will be:

"...commenced on a phased basis to coincide with the ratification of the UN Convention of the Rights of Persons with Disabilities later this year."

Infographic: Overview of the Assisted Decision-Making (Capacity) Act 2015

What you need to know about the

Assisted-Decision Making (Capacity) Act 2015

Establishes a

Decision Support Service (DSS)

within the

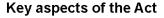
Mental Health Commission





Functions of the DSS:

- Public awareness
- Developing codes of practice
- Information and guidance
- · Advising state bodies
- Keeping records and reports
- Making investigations





A person-focused, flexible approach to adults who cannot make decisions without help.



Abolishes Wards of Court system & repeals

Lunacy Regulation (Ireland) Act 1871 and Marriage of Lunatics Act 1811.



Review of all existing wards to either discharge or transition to the new structure.



Legally recognised **decision-makers** to support vulnerable people.



Advance Healthcare Directive – made to come into effect if the author subsequently loses decision-making capacity.

Source: Oireachtas Library & Research Service (2017)

Volume of Wardship cases in 2014/2015

The Department of Justice and Equality expects that the demands placed on the new system will be greater than that which existed for the Wards of Court system.⁹ The following tables show the number of Wardship cases in 2015.

Wardship cases in 2014/2015¹⁰

	2014	2015
Wardship cases	2,014	2,553
Applications awaiting hearing*	78	201
Declaratory orders**	322	237
Dismissed/discharged	160	161
Orders signed	1,458	1,410
* cases pending with inquiry order signe		
** adults and minors taken into Wardship		

General solicitor for minors and wards of	2014	2015
court		
Wardship cases – active (yearly average)	420	438
Wardship cases - pending	10	6
Wardship - dismissal	141	146
Sub cases	296	270

Reason person admitted to	2014	2015
Wardship		
Elderly mental infirm	159 (36%)	155 (36%)
Learning or intellectual disability	122 (28%)	122 (28%)
Psychiatric illness	95 (22%)	96 (22%)
Acquired brain injury	54 (12%)	55 (13%)
Minor	6 (1%)	5 (1%)
Residential abuse	2 (0.5%)	2 (0%)
Total	438	435

Source: Courts Service 2016/2017

The new legislation also repeals the *Marriage of Lunatics Act 1811*, which deems Wards of Court:

"...to be incapable of contracting a valid marriage." 11

Advance healthcare directives

The Assisted Decision-Making (Capacity) Act 2015 provides a legislative basis for advance healthcare directives which may be made by any person with 'capacity' who is aged 18 or over. An advance healthcare directive provides detail on the type of treatment the relevant person wishes to receive in the event that they lose decision-making capacity. It includes life-sustaining treatment. Ireland has never had a statutory basis for such directives before.

The provision for advance healthcare directives in Part 8 of the Act enables a person to refuse treatment, even if this results in death, provided that their directive clearly identifies the type of treatment refused and the circumstances under which treatment will be refused. If refusal of treatment is likely to result in death, the directive needs to state that this is acceptable to the directive-maker.

While a request for specific treatment is not legally binding, a healthcare professional will have to report why they did not comply with the directive.

There are some situations in which advance healthcare directives may not be complied with, such as treatment which is regulated by Part 4 of the *Mental Health Act 2001* ("Consent to Treatment"). Such treatment includes psycho-surgery and Electro-convulsive Therapy (ECT). Also, in cases where a directive-maker refuses treatment in the event of pregnancy (and it is the opinion of the healthcare professional concerned that this may harm the unborn child) an application will be made to the High Court to determine whether or not the refusal of treatment will apply.

Amendments to the Bill as published

The Bill as published on 20th September 2013 was amended to a considerable degree by the Houses of the Oireachtas. The Bill was signed into law by the President on 30th December 2015. The Oireachtas L&RS previously published a <u>Bills Digest</u> which provides further background on the Bill.

New decision-making supports supervised by the DSS



<u>Decision-making assistant</u> will assist but decision-making responsibility remains with the relevant person.



Degrees of support

<u>Co-decision-maker</u> will make decisions jointly with relevant person.

3

<u>Decision-making representative</u> will work with people who are unable to make decisions even with help.

Source: Oireachtas Library & Research Service (2017)

Other roles within the Decision Support Services (DSS)

In addition to the three new decision-making supports outlined above, the DSS can appoint (and establish a panel of) suitable persons willing to act as:

Special visitor: someone with a particular knowledge, expertise, or experience around capacity issues. This could be (but does not have to be) a medical practitioner.

General visitor: someone who has a relevant qualification, expertise or experience that might assist the director in his/her supervisory functions.

Both special and general visitors may assist the director in carrying out his/her duties and may be involved in fulfilling any of the decision-making roles provided for by the Act; writing reports, interviewing the relevant person or examining their health, personal or financial records.

Court friend: the Director can appoint a 'court friend' where there is no other decision-maker available. The court friend will assist the relevant person in making an application, as well as submissions, to the court.

Areas of responsibility under the new legislation

While the Act primarily deals with legal issues, the Decision Support Service will be situated in the Mental Health Commission (MHC) and the Director of the DSS will submit reports to the MHC and the Minister for Health. In October 2016 the Minister for Justice and Equality, Ms. Frances Fitzgerald, T.D. stated that the budget for the DSS, as well as the mechanism through which its funding will be supplied, was being dealt with as part of the 2017 Estimates process. The 2017 revised estimates do not provide a figure for the DSS specifically but reports that the budget for the Mental Health Commission is €13,974,000 for 2017, the same as for 2016.¹² Table 1 explains some of the main areas that fall under the respective Departments of 'Justice' and 'Health'.

Table 1: Responsibilities of bodies/persons under the aegis of the Department of Justice and the Department of Health

Department of Justice and Equality		Department of Health		
Minister for Justice and Equality	Make regulations under the Act and oversee review of the Act.	Minister for Health	Receive and lay reports by the Decision Support Service before the Oireachtas.	
The Court Service of Ireland	Circuit Court -jurisdiction over assessment of capacity and appointment of some decision-making roles. High Court - jurisdiction over lifesustaining treatment and donation of organs.	Mental Health Commission	Decide the terms and conditions of the Director of the DSS, as well as its staff.	
Office of Wards of Court	Co-operate with the Decision Support Service on the review and transfer of existing Wards.	Decision Support Service	Supervision of decision makers and preparation of reports to the Mental Health Commission and Minister for Health.	

Source: Oireachtas Library & Research Service (2017)

Using performance information to scrutinise the Act

At time of writing a number of sections have been commenced. These are listed here. A review of the Act will take place within five years of its enactment. Once the Act has been commenced and enough time has passed for the main provisions to be implemented, the following indicators may assist in deciding if the legislation is meeting its stated objectives. This table has been prepared by the Oireachtas Library & Research Service and is purely indicative. Notwithstanding that the DSS is not yet established, performance information would require collection by the DSS, the MHC or another responsible agent under the Act. The L&RS has previously published a *Spotlight* on *Parliamentary Scrutiny of Government Performance* which can be accessed here.

Table 2: Performance measurement of the Assisted Decision-making (Capacity) Act 2015

Objective	Activity	Output	Interim	Final	Evaluation
			Impact	Impact	
1. Meet obligations under Article 12 of the UNCRPD (equal status	Replace Wards of Court system with a modern statutory framework overseen by the Decision Support Service (DSS).	Establishment of the Decision Support Service.	Ireland ratifies the UNCRPD.	Improved system for those affected.	Reports from the United Nations Committee on the Rights of Persons with Disabilities
before the law)	Review of existing Wardships.	The number of cases discharged from Wardship or transitioned to the new system.	Wardships phased out.	Relevant persons afforded more rights.	Reports by the DSS.
2. Safeguard against abuse.	Investigations by the DSS.	The number of investigations made by the DSS and the outcome of these.	A higher proportion of abuses detected and dealt with.	Dignity and justice for relevant persons.	Details will be provided in reports by the DSS.
3. Improve accessibility.	Transfer jurisdiction from the High Court to the Circuit Court for most issues.	The number of cases treated by the Circuit and High Courts.	More people who need support receive it.	A more timely and affordable system. Copes more effectively with expected increase in demand.	Courts Service/Reports by the DSS.
	Relevant Persons will receive legal aid, subject to means restrictions, when making certain applications to the court.	The number of persons accessing legal aid for capacity cases.	Legal costs are reduced to the applicant.	The new system is more accessible.	Legal Aid Board/Reports by the DSS.
4. Create Codes and Procedures for health and social care workers as well as decision- makers.	Consultation with relevant stakeholders and drafting of codes and procedures	Codes and Procedures providing guidance are published.	Parties know how the legislation works and how to work within its framework.	More certainty and greater probability of the legislation being implemented successfully.	Reports by the DSS.
5. Provide public information and increase awareness.	DSS improves public awareness of the new framework.	The Act states that the DSS must establish a website, or other electronic means to disseminate information to members of the public.	The public is aware of the DSS and what it does.	The public is aware of the role of the DSS leading to the service being utilised by the relevant stakeholders.	Reports by the DSS. Website.

Source: Table compiled by the Oireachtas Library & Research Service (2017). Selection of objectives based on RIA and reading of the Act.

Baseline information for some of the above indicators may be found on the Courts Service website (e.g. see pg.6 of this paper for information on Wardships).

Implications of the Act in health and social care

The Act will apply to all health and social care settings. The Act provides that the Director of the DSS may prepare and publish (or request another body to do so) a code of practice which will provide guidance to all decision-makers outlined in the legislation as well as healthcare, social care, legal and financial professionals acting on behalf of relevant persons. In drafting these codes the Director must consult with the Health Service Executive (HSE), Health Information and Quality Authority (HIQA), the National Disability Authority (NDA), and the Citizens Information Board (CIB) (which provides the National Advocacy Service), representatives of professional bodies in healthcare, social care, legal and financial professionals.

To ensure effective compliance and implementation of the new legislation the HSE established a National Assisted Decision Making Steering Group in January 2016. A key aim of the steering group is to develop a code of practice for health and social care and to contribute to the development of other codes through the DSS and Department of Health. Other roles of the Steering Group include:

- The development of an <u>education and training implementation plan</u> for health and social care services.
- The development of an <u>information and communications plan</u> for health and social care services.
- The development of an <u>Advance Healthcare Directive Implementation plan</u> for health and social care services.

In March 2017 the HSE published <u>A Guide for Health and Social Care Professionals</u> The aim of the document is to "provide guidance to enable health and social care staff to implement good practice in relation to the Act."

Ensuring compliance with the legislation

Decision Support Service (DSS)

The DSS, which is to be set up within the Mental Health Commission (MHC),¹ will be the main body tasked with overseeing the implementation of the new legislation. The DSS will

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¹ The Mental Health Commission is an independent organisation set up by the *Mental Health Act 2001* to protect the rights of those detained in approved centres.

supervise the various decision-making roles provided by the Act and handle any complaints made against those who are providing decision-making support (e.g. decision-making assistants, co-decision makers etc.), including attorneys of enduring powers.

The director of the DSS will be appointed by the MHC for a period of six years but may be re-appointed after this. Staff working under the director will be staff of the MHC. The DSS will submit reports on its activities to the MHC and Minister for Health.

The role of the courts

The Circuit Court will have exclusive jurisdiction over almost all issues dealt with under the Act and its work will be carried out by specialist judges. This is a change from the Wards of Court system which was dealt with exclusively by the High Court. Where an urgent decision needs to be made and a person is found to lack capacity (and no decision-maker has been appointed), the Circuit Court can make the decision on behalf of the relevant person under Section 38(2)(a). However, decisions around withdrawal of life-sustaining treatment or donation of an organ from a living donor, will still be decided by the High Court.¹³

The main focus of the Circuit Court will be to declare whether or not a person has decision-making capacity, as well as appointing Decision-Making Representatives.

As noted in the Regulatory Impact Analysis (RIA) accompanying the Bill:

"...moving jurisdiction to the Circuit Court should ensure greater accessibility and lower costs to applicants than if jurisdiction were left with the High Court."

The RIA can be accessed <u>here</u>.

The Act also provides the opportunity to access legal aid for capacity-related cases. Section 52 of the Act:

- amends the Civil Legal Aid Act 1995, so that a party applying under Part 5 of the Assisted decision-making (capacity) Act 2015 may qualify for free legal advice;
- provides that a relevant person may qualify for legal aid;
- provides that the Board may grant a legal aid certificate to a patient who is going before a tribunal under the Mental Health Act 2001.

Significant amendments made to the Bill by the Oireachtas

The General Scheme of the Bill underwent pre-legislative scrutiny by the Joint Committee on Justice, Defence and Equality in 2012. The resulting report can be accessed <a href="https://example.com/here

addition, the following amendments were made to the Bill as published, during its passage through the Oireachtas.

- The Bill as published provided for the establishment of an independent Office of the Public Guardian to replace the Office of Wards of Court. It was intended that this new office would be a part of the Courts service. A number of stakeholders and legislators argued that this was a paternalistic approach and the legislation was amended during the legislative process so that the Decision Support Service, to be located in the Mental Health Commission, would replace the Office of Wards of Court.
- Advance healthcare directives were not included in the Bill as published in 2013 but were introduced, as intended, at Committee stage in 2015. Prior to this, officials in the Department of Health published the draft general scheme of the advance health care directive provisions in February 2014 and conducted a public consultation process on those provisions.¹⁴
- Designated healthcare representative in the context of advance healthcare
 directives, a directive maker can designate someone to exercise the relevant powers.
 Under section 87 of the Act there are restrictions as to who is eligible for such a role,
 similar to those set out for other decision-makers provided for in the Act.
- Co-decision-making agreement whereas the published Bill provided that a court order would be required to approve a co-decision-making agreement made voluntarily between two persons, the Act essentially transfers the responsibility for this approval to the DSS. ¹⁵ Under the Act the relevant person will choose a trusted co-decision-maker and can receive advice and support from the DSS. On drawing up the co-decision-making agreement, the DSS will verify that everything is in order before registering the agreement, whereupon it will come into effect.
- The role of Informal decision makers which appeared in the published Bill were removed during the legislative process. The intention, when drafting Part 7 of the Bill, was to develop provisions to protect persons from liability where they took decisions in good faith, i.e. on the basis of safeguarding the personal welfare of a person with capacity difficulties. However, some stakeholders were concerned that too many rights would be bestowed on this group.¹⁶

Stakeholder recommendations not reflected in the Act

Retrospective review of Wards of Court Funds

The Courts Service Annual Report 2014 states that at the 30th September 2014 the Accountants Office was managing funds valued at €950 million on behalf of 2,600 persons who have been declared Wards of Court. A Public Accounts Committee

(PAC) Report on Wards of Court Funds (2015) found that many Wards of Court had experienced losses to their funds during the financial downturn. Inclusion Ireland called for a retrospective review of Wards of Court funds. While the legislation does not provide for any review, the Minister for Justice and Equality, Ms. Frances Fitzgerald, T.D. stated on 16 September 2016 that an independent review was underway. This review was published in November 2016 and can be accessed here. The authors of the report found that Spectrum Growth Fund was an appropriate investment strategy and that while many Wards suffered losses during the financial crash, equity exposure was less than that of comparable funds.

The Mental Health Act 2001 provides that a person who is admitted to an approved centre as an involuntary patient is entitled to legal representation and a tribunal hearing, within 21 days of their detention. The Act, however, does not take mental capacity into account when deciding who is a voluntary patient. Effectively this means that a person who does not have decision-making capacity can be considered a voluntary patient and is therefore, not entitled to the same safeguards as an involuntary patient. The Oireachtas Library & Research Service previously wrote a Spotlight on the Mental Health Act 2001 which can be accessed here.

While some stakeholders recommended that the Capacity legislation should deal with this issue, the then Minister Kathleen Lynch stated that this would be dealt with under the review of the *Mental Health Act 2001*. The Expert Group review of the MHA 2001 was published on 5th March 2015 and the Minister's press release accompanying the publication can be accessed here. Minister Lynch secured approval to proceed with a general scheme of a Bill to amend the *Mental Health Act 2001* based on the recommendations of the Expert Group report. On 1st February 2017 the Minister of State at the Department of Health, Ms. Helen McEntee, T.D., said that the Department is preparing the General Scheme of a Bill which will reflect the recommendations of the Expert Group.¹⁹

• Multi-disciplinary tribunals

Some commentators have expressed regret that there are no provisions in the legislation for Multi-disciplinary tribunals, similar to those under the *Mental Health Act* 2001, which they argue would be more suitable than a court in dealing with capacity issues.

DSS should be an independent statutory body

Some stakeholders have expressed concern that the DSS is to be situated in the MHC as that body is under the aegis of the Department of Health. Some stakeholders argued that it should be independent. In December 2015, the then Minister of State, Ms. Kathleen Lynch, T.D. stated that:

"We decided that the Mental Health Commission was the right place because it has the expertise and understands the functioning of capacity."20

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¹Written answer to Parliamentary Question, ref no. 14844/17 on 28 March 2017

² Inclusion Ireland. (2016). Capacity. Accessed on 16 May 2017 at http://www.inclusionireland.ie/capacity

³ HRB. (2015). Statistic series 30: Annual Report of the National Intellectual Disability Database Committee 2015. Accessed on 16 May 2017 at http://www.hrb.ie/uploads/tx_hrbpublications/NIDD_2015_Annual_Report_web.pdf lbid.

⁵ Brí. (2017). Brain Injury Statistics in Ireland. Accessed on 9th May 2017 at http://www.briireland.ie/statistics/

⁶ United Nations. (2003). Progress of efforts to ensure the full recognition and enjoyments of the human rights of persons with disabilities – Report of the Secretary-General. Accessed on 16th May 2017 at https://www.un.org/development/desa/disabilities/resources/general-assembly/progress-ofefforts-to-ensure-the-full-recognition-and-enjoyment-of-the-human-rights-of-persons-with-disabilitiesreport-of-the-secretary-general-a58181.html

⁷ Inclusion Ireland. (2011). International Conference at the University of British Columbia, Vancouver, Canada - April 2011: Gerard Quinn: 'Rethinking Personhood: New Directions in Legal Capacity Law & Policy' Accessed on 15th May 2017 at http://www.inclusionireland.ie/sites/default/files/attach/basic- page/846/rethinkingpersonhood-newdirectionsinlegalcapacitylawandpolicy-gerardquinnapril2011.docx

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11 Matthews, F. (2015). Cognitive Impairment and the Capacity to Marry. Irish Journal of Legal Studies, Vol 5(2). Accessed on 16th May 2017 at http://ijls.ie/wp-content/uploads/2015/09/Vol_5_Issue_2_Article-3-Matthews-Cognitive-Impairment.pdf

¹² Written answer to Parliamentary Question, ref no.29461/16

¹³ electronic Irish Statute Book. Assisted Decision-Making (Capacity) Act 2015. Accessed on 16th May 2017 at http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/print.html

¹⁴ Select Committee on Justice, Defence and Equality Debate. (2015). Assisted Decision-Making (Capacity) Bill 2013: Committee Stage. Accessed on 16th May 2017 at http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/committeetakes/J US2015061700002?opendocument#A00100

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ Inclusion Ireland. (2015). Inclusion Ireland welcomes historical passing of the Assisted Decision-Making (Capacity) Bill 2013. Accessed on 15th May 2017 at

http://www.inclusionireland.ie/content/media/1394/inclusion-ireland-welcomes-historical-passingassisted-decision-making-capacity

18 Written answer to Parliamentary Question, ref no. 26158/16 on 16th September 2016.

19 Written answer to Parliamentary Question, ref no. 4502/17 on 1st February 2017.

²⁰ Dáil Éireann Debate 17 December 2015. Accessed on 16th May 2017 at http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail20151217 00015?opendocument