



**Isle of Man**  
Government  
*Reilrys Ellan Vannin*

# Department of Health and Social Care

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*Rheynn Slaynt as Kiarail y Theay*

## **Summary of Consultation Responses on: Capacity Bill 2021**

**June 2021**

Delivering Longer  

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**Healthier Lives**

HEALTH AND  
SOCIAL CARE IN  
THE ISLE OF MAN  
2016 - 2021  
5 YEARS. 5 GOALS.



## **We Asked**

We, the Department of Health and Social Care (“the Department”) invited everyone, including members of the public, health and care practitioners, other Government Departments and stakeholders to participate in this consultation.

The purpose of this consultation was to seek views on a draft Capacity Bill 2021 (“the Bill”) which aims to introduce a comprehensive legal framework to the Island to safeguard individual rights, dignity and the wellbeing of persons who may lack capacity and further bring the Island’s legislation in line with recognised best practice.

In addition, a further consultation ran concurrently to the general consultation, that of the ‘Hard to Reach’ groups – who are those people unlikely to be able to contribute to the general consultation in the usual way, without additional support. However, due to the immediate and direct impact that the proposed legislation will have on their lives, it is essential that their views are heard. A supplementary report addressing the outcomes of the ‘Hard to Reach’ consultation, is included at Appendix 2.

The public consultation on the Bill began on 25 February 2021 and ended on 08 April 2021.

## **You Said**

The consultation received a total of 69 responses. Of those responses, 60 were via the online consultation hub and a further 9 were received separately by email.

On the whole there was strong support confirming the need for a clear legal framework with robust safeguards for people who may have lost the capacity to make decisions for themselves.

Overall, content of the Bill was supportive. Some respondents shared their personal experiences of dealing with the issues surrounding capacity, which we found helpful.

## **We Did**

The Department welcomed all feedback and considered each comment made in response to the consultation. As a result of which, a number of amendments will be made to the draft Bill. Once the Bill has been finalised, it will be presented for consideration by the next Council of Ministers, with the aim to introduce it into the branches of Tynwald early in the next Administration.

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## 1. Background

The Capacity Bill will govern decision-making for individuals who may have lost the capacity to make decisions for themselves, it will provide assurance that they will be supported to make decisions for themselves wherever possible, and where it is not possible, that any decisions made on their behalf, are done so in their best interests.

In the Autumn of last year the Department ran an 8 week public consultation, the purpose of which was to seek views and, where relevant, evidence to support those views on the policies that would shape the Island's new capacity legislation.

Having carefully considered and analysed the responses that were received from that consultation, the Department published a "[Summary of Consultation Responses on Capacity Policy Principles](#)".

Overwhelmingly, there was strong support in favour of a modern and clear legal framework for people who may have lost the capacity to make decisions for themselves, and a general consensus as to what the overarching capacity principles underpinning the Capacity Bill 2021 should be.

Following that consultation, policy work was undertaken and the responses were used to inform and shape the Capacity Bill 2021 – which was the subject of this Consultation.

## 2. Report Format

The consultation was made up of open questions, to offer people the opportunity to give detailed, in-depth answers. This was really helpful, many responses were very comprehensive and whilst some stretched beyond the remit of the immediate consultation, all responses will be used to inform discussions on later stages of policy development for Phase 2 and the Code of Practice.

## 3. Summary of Responses

### 3.1 May we publish your response?

Yes, you can publish my response in full	22	36.67%
Yes, you may publish my response anonymously	29	48.33%
No, please do not publish my response	9	15.00%
Not answered	0	0.00%

### 3.2 Do you have any comments on the overarching principles and the preliminary clauses of the Bill? (CLAUSES 3 TO 11)

There were 42 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
1.	No, they sound sensible and in tune with the UK legislation.	The overarching principles are in line with the Mental Capacity Act 2005 "MCA 05" (an Act of Parliament), however the Bill and the individual provisions therein, has been drafted with the Island's individual ethos and unique demographic in mind. It has also addressed some of the weaknesses which have been identified in the MCA 05.
2.	Totally agree with stressing the importance of people being allowed to make their own decisions on their lives unless we can be sure they are unable to.	Thank you for your contribution.
3.	Generally in agreement. Clause 6 goes on to list particular steps that must be taken. The decision-maker must consider whether the individual concerned is likely to have capacity at some future date. This is in case the decision can be put off, until the person can make it himself. (SHOULD THIS BE THEMSELVES OR OTHER NEUTRAL DESCRIPTOR?)	The Bill makes provision for the decision maker to consider putting off decisions until a future date - clause 6(3) states that "D must consider whether it is likely that P will at some time have capacity in relation to the matter in question, and if it appears likely that P will, when that is likely to be".
4.	Improvement to and upgrading the protections afforded to those lacking capacity is welcome.	Thank you for your contribution.
5.	Clause 5: "retain information for an appropriate period (subsection (3) then provides what an appropriate period of time is)" -This is unclear. Generally, in assessing capacity the basic principle is that the person can retain the information long enough to arrive a decision. The fact that they then cannot recall the decision they made does not mean that they lack capacity, as long as they consistently arrive at the same decision utilising the same reasoning process. I wonder if this could be worded better?	<p>The retention period is proportionate and is weighted against the nature of that decision.</p> <p>The Department agrees with the statement that just because a person cannot, at a later date, recall making a decision does not mean that at the material time that they lacked the capacity to do so.</p>

### 3.3 Do you have any comments on the proposed statutory form of power of attorney? (CLAUSES 12 TO 20)

There were 34 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
1.	Extension of the law provided by LPAs is an important addition to the legal framework.	Thank you for your contribution.
2.	I would prefer if a medical professional was part of the assessment of the lack of capacity and involved in the decision to enact an LPA.	<p>The role of the certificate provider will be prescribed by regulations made under Schedule 1, Part 1, 2 (d). The responses received from this consultation will form part of the discussions when determining the status of the certificate provider.</p> <p>Further, the Department will be consulting again on the regulations themselves prescribing the role of the certificate provider.</p>
3.	<p>I have concerns about the bankruptcy requirement on potential LPA's when they are not responsible for assets etc. it feels like an arbitrary requirement.</p> <p>I also don't believe there is enough in place to stop the potential abuse of this system as it currently stands. It implies that the donee is allowed to determine whether the doner is capable of making the decision or not.</p>	<p>The restriction on a person who is, or has been subject to bankruptcy proceedings acting as a donee, applies only to Property and Finance LPAs – not Health and Welfare LPAs.</p> <p>Clause 13(3) ensures that the Department will make regulations specifying who may not be appointed to act as a donee – effectively it will only be those deemed fit and proper who can act as such.</p> <p>Safeguards included within the Bill and the accompanying Code of Practice will facilitate the exercise of all safeguards.</p>

<p><b>4.</b></p>	<p>1) This may be covered in the forthcoming D.O.L safeguards section, but will there be specific guidance in the Code of Practice or the DOL s part of the legislation to determine at what point “proportionate restraint” if applied repeatedly becomes formal “deprivation of liberty”. i.e., when does restraint become DOL?</p> <p>2) In certain cases where there may be remitting and relapsing Mental Illness, such as Psychosis or Bipolar Disorder, patients often lose their confidence and can become vulnerable to coercive control ( e.g. by a partner or parent), even when fully well. The Commission would like to see strong safeguards in place, which are not dependent on the donor having to instigate a potentially daunting process, where they can regain full control of their affairs when they are well.</p>	<p>Yes, alongside independent capacity representation, liberty protection safeguards will be covered as a part of a second phase of work on the Island’s capacity legislation. This will be supplemented by an amended Code of Practice.</p> <p>At any stage, a donor can legally take back control of their affairs from their donee. There is no legal process required to do this – provided the donor has the capacity to make the decision in question (unless they wish for the donee to continue to assist in some aspects of their affairs, in which case it will be on the donors terms).</p>
<p><b>5.</b></p>	<p>The new statutory form of power of attorney appears to be much more useful in that it now covers health and welfare as well as property and monetary affairs - so it is much more wide-ranging and provides more protection for the vulnerable individual and more peace of mind to their carer/s.</p>	<p>Thank you for your contribution.</p>

### 3.4 Do you have any comments on the proposed powers of the Court or delegates appointed by the Court? (CLAUSES 21 to 27).

There were 32 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
1.	My only comment is that I have the power to appoint who I want as my "delegate". My Civil Partner and I have the current Power of Attorney, naming each other as our appointed Representative/delegate/attorney. We would want this to continue without any problems. We have known each other for 60+ years and know each other's wishes.	All existing EPAs will continue to have affect under the Capacity Bill 2021.
2.	<p>Often a lack of POA is due to not expecting a loss of capacity etc.</p> <p>It is not clear that if, in the first instance, family members or NOK are considered a delegate prior to court/court identified delegates/trust.</p>	<p>The Department acknowledges that much work will need to be undertaken at the implementation stage, the better understanding people have of the capacity legislation and the accompanying Code of Practice; the greater the success of the Capacity Bill.</p> <p>Furthermore, the more people that use and access the new Lasting Power of Attorney provisions – the less the requirement for court appointed delegates there will be.</p> <p>Only in the event that the person does not have a valid LPA would the Court seek to appoint a delegate.</p> <p>If there is no valid LPA, then in the first instance, there would be an expectation that the Court would appoint a family member or suitable next of kin, if required, as the delegate.</p>
3.	No this seems comprehensive.	Thank you for your contribution.



<p><b>4.</b></p>	<p>What happens where there is a disagreement between 2 delegates?</p> <p>How is the review of capacity undertaken and how are delegates supported to ease back on control?</p>	<p>Under the proposed functions set out at clause 28(a), the Attorney General will have the power to supervise delegates. We believe that this general provision will provide sufficient powers to adjudicate disputes that cannot be resolved between two Court appointed delegates.</p> <p>We will however, verify with Chambers that clause 28(a), is adequate for this purpose.</p> <p>Further, the Code of Practice will include provision regarding dispute resolution between delegates (and donees).</p> <p>There is an ongoing duty on all decision makers to review capacity in relation to each material decision (clause 26(1)).</p> <p>Therefore a delegate does not have the power to make a decision on behalf of a person in relation to a matter, if the delegate knows, or, has reasonable grounds for believing the person has capacity in relation to the matter.</p> <p>Full guidance and support will be provided in the accompanying Code of Practice.</p>
<p><b>5.</b></p>	<p>What checks will be carried on the delegates to ensure they are fit &amp; proper for carrying out the decisions they will take and will the checks be carried out at regular intervals to ensure that the delegate is acting correctly?</p>	<p>This is a good point. The Bill at clause 22(3) states that the powers of the court are subject to the provisions of this Act (in particular clause 3 "Principles" and clause 6 "Best Interests").</p> <p>The Department will be considering whether the regulations made under clause 13(3) specifying who can act as a donee, should apply to court appointed delegates.</p>

### 3.5 Do you have any comments on the proposed functions of the Attorney General under the Bill? (CLAUSES 28 to 32)

There were 24 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
1.	This is fine assuming that data protection laws will continue to force the AG to destroy records at a time they are no longer needed.	The Attorney General's Chambers are, as a data controller, subject to all relevant legislative provisions regarding the protection of data.
2.	Decisions made for an individual should not be taken out by a sole person, more than one person needs to be involved in best interests, as well as where possible bringing the person with limited capacity into the discussion	The Capacity Bill allows for more than one person to make decisions, but, there is no requirement for there to be more than one person.
3.	Attorney General has a conflict, he should be excluded from any matter regarding capacity. AG acts for the IOM Government not the public. It should be an independent party.	Her Majesty's Attorney General is the principle legal adviser to the Crown and already has a number of independent public interest functions, for example the referencing of unduly lenient sentences to the Court of Appeal.  Here, the key principle is independence from the parties involved.
4.	Will the vulnerable person be allocated an Independent legal advisor or independent guardian support	The role of the donee and delegate will be to act on behalf of the vulnerable person in relation to the matters in which they are appointed – the donee and delegate, may, on behalf of the person they represent, seek legal advice as appropriate.
5.	We note that section 28 (C) below gives the Attorney General the authority to deal with how a donee of a lasting power of attorney is exercising their powers.	The initial and ongoing support for donees is something that the Department will continue to discuss and work towards in the process of implementing a framework of provision for both donees and delegates.

	<p>However, neither the Registrar General nor the Attorney General seems to have the responsibility of supporting donees to discharge their duties and this is an omission that ought to be rectified if the benefits of an LPA system are to be maximized.</p>	<p>The Code of Practice that will accompany this Bill, will provide guidance and advice for donees.</p> <p>We appreciate your advice – ensuring the benefits of the LPA system is maximised, is of paramount importance and is integral to the overall success of the legislation.</p> <p>The Department will give this further consideration.</p>
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### 3.6 Do you have any comments on the proposed provisions regarding advance decisions to refuse treatment? (CLAUSES 33 to 35)

There were 32 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
<p><b>1.</b></p>	<p>Also, if the person to whom the advance decision applies has acted in a way that is clearly inconsistent with the advance decision then it becomes invalid'</p> <p>This is very important and I am glad this is in here.</p>	<p>Thank you for your contribution.</p>
<p><b>2.</b></p>	<p>If a person with no insight into their mental illness made an advanced decision, when they were deemed to have capacity, to have no treatment how would that work? Surely insight is needed to make an advanced decision when dealing with chronic enduring mental illness like paranoid schizophrenia?</p>	<p>Clause 34 (validity and applicability of advance decisions) of the Bill sets out a number of safeguards for people making advance decisions.</p> <p>Clause 34(4)(2)(c) provides that an advance decision is not valid if the person has done anything else clearly inconsistent with the advance decision remaining that person's fixed decision.</p>
<p><b>3.</b></p>	<p>Am pleased that advanced decision is being taken into account; we just need all island documentation to that effect. Suggest RESPECT documentation.</p>	<p>The form in which advance decisions will be valid will form part of implementation, your comment will inform discussions on the work still to be undertaken in this respect.</p>

4.	Family / parents of adults who have close knowledge/ care of the person, their opinions must be taken into account.	If a person has capacity, (within the meaning of the Capacity Bill) then, any decisions will be solely down to the person – no other opinions will be taken into account.
5.	<p>This seems to state that an advanced decision can be over-ridden by the donee if the person then loses capacity. I do not agree with this- the clearly expressed wishes of the person should stand and not be overridden.</p> <p>This would also put doctors in a very difficult position if there was a clear advanced decision, but the donee wished to proceed against the advanced decision.</p>	<p>An Advance decision of a person cannot be overridden by a donee.</p> <p>However if the donor makes a Health and Welfare LPA after making an advance decision and the two differed the LPA, as the latest document, would be taken to be the express wishes of the person</p> <p>The most recent instrument will always replace the previous instrument – unless, as stated above, it is made in anticipation of upholding the previous instrument.</p>

### 3.7 Do you have any comments on the proposed provisions of the Capacity Bill regarding excluded decisions, research and the offences of ill-treatment and neglect? (CLAUSES 39 to 43)

There were 25 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
1.	It should be regulated and have a proper complaints procedure. The current DHSC complaints procedure is unregulated and not fit for purpose.	The Department is currently undertaking a review of its complaints procedure and is committed to introducing legislation early on in the next Administration.
2.	Will some form of learning be available to delegates so ensure they fully understand what they are signing to undertake	Thank you for your contribution, this is very important, the understanding of legislation is vital to the overall success of the Capacity legislation. The Code of Practice together with the implementation work-stream will provide delegates with full guidance as will the Court appointing them.
3.	Good. Well overdue	Thank you for your contribution.
4.	The term "intrusive research" is not grounded here. Subsection (7) allows for DHSC to make regulations which define the term, but it is not clear that it is DHSC who would satisfy this role. If responsibility for research was located elsewhere, this might need amendment so that the regulation making powers are correctly placed.	Thank you for your contribution. This is a provision that will require some further work and will form part of our revised drafting instructions.

### 3.8 Do you have any comments regarding the provisions proposed regarding the Code of Practice? CLAUSES 44 to 45

There were 22 responses to this question.

	<b><u>A sample of comments received included:</u></b>	<b><u>Department's response:</u></b>
1.	All Codes of Practice should have public consultation and require Tynwald Approval.	Thank you for your contribution, yes in accordance with the procedures set out in clauses 44 and 45 of the Bill, the Department are required to consult on the Code of Practice and it will be laid before Tynwald.
2.	<p>The summary of the Bill included in this consultation is useful.</p> <p>But with another consultation planned for the codes of practice, what's the point of this one?</p> <p>The 2020 consultation showed overwhelming support.</p> <p>Please get on and enact it!</p>	<p>Thank you for your contribution.</p> <p>The purpose of this consultation was to gather views and comment on the provisions of the proposed Capacity Bill by the people who are affected day to day, as well as those organisations who contribute to the care and protection of people, affected by capacity issues.</p> <p>It is a legislative requirement that the Code of Practice is consulted on.</p>
3.	I think the code of practice will be extremely helpful. So I think people should use it.	Thank you for your contribution.
4.	I agree that a thorough and readable Code of Practice is essential to those who will be implementing the Act. The MCA Code of Practice is an excellent example of how one can support the Act from the Understanding of the principles, assessments, best interests and the legal context.	Thank you for your contribution.

## 4. Conclusion

Overall, the Capacity Bill 2021 has been well received, with the majority of proposals receiving support. The consultation received a total of 69 responses. Of those responses, 60 were via the online consultation hub and a further 9 were received by email.

There was an overriding feeling that this project is long overdue and should now be expedited so that the legislative capacity framework can begin safeguarding those most vulnerable people in society. There was a real emphasis of support for the provisions of the Bill but with the overriding objective that all safeguards are comprehensive and effective.

The purpose of the Bill is to make capacity legislation accessible to everyone, the success of this project will be measured by how accessible and “user-friendly” the provisions of the legislation are and how closely the “Best Interests” decisions are delivered by the people, who are acting on behalf of someone who is unable to make decisions independently. This work will be facilitated by the accompanying Code of Practice, which will provide vital guidance in the implementation of the Capacity Act in day to day life.

Some of the responses that the Department has received, will require further attention, and ongoing work is being undertaken in this respect. All submissions will be taken into consideration when developing revised drafting instructions and finalising the provisions of the Capacity Bill 2021.

Additionally, a number of the submissions were very comprehensive and will be used to inform discussions on later stages of policy development for Phase 2 and the Code of Practice.

One significant thing that this consultation has highlighted, is that this is an incredibly complex, technical and emotionally challenging area of law and has emphasised even more, the importance of a very clear, comprehensive and “user friendly” Code of Practice to accompany and facilitate the legislation.

The Department would like to express their appreciation to everyone who took the time to respond to this consultation. We have attempted to address all the comments within this report to provide you with an idea of how the Department have processed your comments, and give an indication of what action is likely to be progressed in light of the consultation responses provided.

## 5. Next Steps

This consultation has contributed to the decision-making process, the responses received have raised valued points which the Department have taken into account. The next step will be to start the process of amending the draft Bill.

Once the Capacity Bill has been amended and a final draft has been approved by the Department with the aim of introducing it into the branches of Tynwald during the early part of the next administration.

We have considered each response submitted, however for the purposes of this Consultation Report, we have not included a response to every comment – instead, a sample of comments, which we feel are representative of the over-all contribution, have been included and the full list of responses, where you have indicated that we can publish, are in the appendix attached to this report.

However, if you have responded to the consultation and feel that your comment or concern has not been addressed, please contact us in one of the following ways:

Email: [dhsconsultation@gov.im](mailto:dhsconsultation@gov.im)

Telephone: 685816

Address: Crookall House, Demesne Road, Douglas, Isle of Man, IM1 3QA



**APPENDIX 1 – FULL (ANONYMISED) ONLINE RESPONSES<sup>1</sup>**

	COMMENT
	<b>COMMENTS OF THE PRINIPLES – CLAUSES 3 to 11</b> <b>Do you have any comment on the overarching principles and the preliminary clauses of the Bill?</b>
1.	Yes. My mother was 75, a cancer patient, was on an operating table at Nobles. The consultant noticed that she had not signed a DNR and refused to operate until such time as Mum signed a DNR. The Nurse on duty detailed what happened clearly in her notes (running to approx an A4 page). The Consultant requested a Registrar come down with the DNR form, the Registrar refused so someone else was asked to attend. Mum was on the table and witnessing this. This is all recorded in detail. I raised this as a complaint with DHSC in August 2019, to date they have failed to admit that my Mum was left in an untenable position, sign the DNR or we do not operate. It was a procedure required to band life threatening varices caused cancer. The cancer had been missed by A & E, and two urgent admittances to Nobles for blood transfusions. Nobles kept promising to scan and didn't, the cancer grew and Mum died. Please don't indicate in your procedure notes that DNRs for cancer patients are not compulsory because they are in some circumstances. For years I acted as a go between between health professionals and Mum because she suffered anxiety. My Mum was petrified of Nobles after that procedure. She didn't get an apology either. In addition to which DHSC think it is acceptable for a Nurse to advise an elderly cancer patient with sepsis that treatment is being withdrawn and she will effectively be left to die, no more chemo. Again this was raised a complaint with DHSC about the notes made by a Ward Doctor asking the Nurse to return my calls being ignored. This was not resolved either. I have serious concerns that the management at DHSC can handle this capacity bill. The AG should be excluded, he acts for the Government and not for the general public.
2.	Get on with it. Lasting Power of Attorney was introduced in 2007 in England to replace Enduring Power of Attorney.
3.	No particular comment except that if it basically follows the UK Capacity Acts and requirements for their LPA (Health & Welfare and Financial) which I am familiar with that is fine.
4.	No. The principles and clauses seem appropriate.
5.	If someone understands, can retain and weigh the information relevant to a decision but is unable to communicate their decision, what safeguards will be in place to ensure that their will is heard and adhered to? How will communication be aided?
6.	Children under 16 must not be automatically excluded from making decisions about their care. Gillick Competence should be used, see Gillick v West Norfolk and Wisbech AHA [1986].
7.	They appear very insightful and thorough for the individual ensuring safety and well-being without over restricting participation in decision making.
8.	Who will decide when someone needs support, what form will be required to define the incapacity . Letter from Psychiatrist, General Practitioner. Currently an Enduring Power of Attorney is not acceptable in Small Claims Court. How general will the definition be of incapable/difficulty in using logic/being unable to argue for themselves/ organisational difficulties or feelings of oppression in a strange environment ( Court) ?
9.	Nice ideas. Will need not to make more bureaucracy the overriding outcome. Does this mirror uk or even eu law /principles?
10	Glad that we are at last getting law around capacity and changing to lasting power of attorney rather than enduring.
11	who makes the best interest decision and the lack of capacity. Will it be possible for front line emergency staff i.e. Police, Ambulance, Doctors and Nurses to do a capacity test, to make a judgement and take action in the best interest of the person who is currently deemed to not have capacity . Without the need to section them under the mental health act.
12	Is fluctuating capacity taken into consideration i.e. alcohol/drug addiction, where a 'later date being planned may also not be possible'

<sup>1</sup> All “do not publish” responses have been removed.

13	Would it be possible to add the awareness around unwise decisions, to emphasise that a person may make an unwise decision, however this does not mean they are lacking capacity etc.
14	No, they sound sensible and in tune with the UK legislation.
15	Where is the Independent assistance principle?
16	<p>No, save it is not clear why a child should be presumed to have capacity. The presumption may work for a person who is plainly an adult but the presumption is too wide if the drafting reflects this principle ( clause 3). Distinction should be made between mental capacity and contractual capacity.</p> <p>The bill purports to repeal all of the 1983 Act why?</p>
17	The above set out the principles much more clearly than at present. Thought should include that capacity may vary depending on the issue or topic - and that people without capacity still have the right to refuse and not be forced to do something against their will.
18	<p>**** If a person who fits the criteria viz: psychiatric illness, severe memory loss, learning disability, possible schizophrenia, DOES NOT ALLOW family member to be designated as official/legal "carer", never mind "power of attorney", what happens then? Does the Bill cover this very real problem?</p> <p>Having spoken to Mr David Ashford in September 2020 with my sister, regarding her son who is only 24 and who is adamant that he will not allow her to be called his "carer" we were all at a loss as to what to do regarding his "incapacity". This problem is currently most acute when he attends his psychiatric appointments and my sister is not allowed to attend the meetings with him, to make sure that the correct information gets shared with the psychiatrist! In the past, critical information has not been shared and it has taken years to get to the point where my sister is even allowed into the end of the meeting, ...literally for the last 5 minutes, and all she is allowed to do is ask the psychiatrist if new, key information ( viz: critical new psychiatric symptoms) has been shared by her son.</p> <p>If my sister had been able to attend critical meetings with her son in the past we might be a lot further on with his treatment plan and support. We are very concerned as to how the new capacity regulations can address this particular problem. Mr Ashford did tell us that we are not alone in having a young family member who lacks capacity, yet at the same time, is blocking his closest family (mum or dad) from being legally allowed to help make decisions.</p> <p>Our main worry is that our young family member, who has these issues, will be catered for when all the older family members are no longer alive to look after him. It is very doubtful whether someone like him will ever be able to live unsupported (job, home etc)</p>
19	No, it appears to mirror UK LPA regulations which are very thorough
20	<p>Can you advise the principles to be applied for residents who have nothing in place and no family, or if the family dispute the best interest decisions applied by a carer.</p> <p>Is there a Independent guardian to oversee disputes in respect of best interest decisions or application.</p>
21	<p>Clause 3 sets out people have capacity from the beginning is perfectly stated.</p> <p>Clause 4 the specific instances my capacity may vary need to be set out and clearly marked. There should be allowances to make sure that capacity can be reinstated when someone is able to do so again. This will involve regular checks.</p> <p>Clause 5 focus on making sure that everyone has been given the appropriate information in the most appropriate format to their condition, it is important that this is known on a personal approach with each new person.</p> <p>Clause 6 it should be discussed what possibilities are usually gonna be used for best interest, in whose best interest will most decisions be made – the person without capacity for the decision-maker. The best way to remove bias</p>

	from best interest, will be to have multiple decision-makers, with varying stakes in the capacities life – doctors, lawyers, social workers.
22	<p>We agree with the proposed two-staged test for capacity as per clause 3(2), 4 and 5. This codifies the current common law position.</p> <p>For clause 5(5), please confirm what will be considered as a ‘short period’ of time in respect of retention of information when making a decision?</p> <p>In addition, it should be clear in the legislation that the test should be conducted at the material time in relation to any decision-making.</p>
23	Totally agree with stressing the importance of people being allowed to make their own decisions on their lives unless we can be sure they are unable to.
24	<p>Generally in agreement.</p> <p>Clause 6 goes on to list particular steps that must be taken. The decision-maker must consider whether the individual concerned is likely to have capacity at some future date. This is in case the decision can be put off, until the person can make it himself. (SHOULD THIS BE THEMSELVES OR OTHER NEUTRAL DESCRIPTOR?)</p>
25	<p>Concerns that an adult who is totally unable to speak or communicate needs or wishes / severe learning difficulties who has always lived with parents / family members / loved one, will have the decision making for them / actions in their best interests will be taken away from their parents / family who have always loved and cared for them. Concerns that The parents / family who know their likes / dislikes personal preferences better than anyone will be disregarded in the decision making process of acting in their best interests as already happens in UK. .</p> <p>Concerns that if parents / family need to represent their wishes or ability to prove that they act in the adults best interests need to prove this in a court of law but cannot afford legal representation or are not entitled to any legal aid then they will not be able to get any legal representation in the court.</p>
26	I think that it is an incredible new article and the government have published it incredibly well definitely. 😊😊😊😊😊😊
27	<p>There should be a provision for an independent Best Interests Assessor to be involved, as is in the UK.</p> <p>It is also essential that professionals, such as Speech and Language Therapists, are regularly consulted to support with capacity assessments to ensure the information provided is accessible and the person is able to clearly communicate their decision as this might not always be verbally. It is essential every professional involved in capacity assessments understands and appreciates ALL forms of communication are valid, not just verbal.</p> <p>It should also be highlighted people who have been assessed to have capacity are able, and have the right to make unwise decisions and these should be respected.</p> <p>DOLS assessors are essential and should also not just be Social Workers, there should be a variety of professionals appointed as DOLS assessors. This should also be said for Best Interests Assessors again these should not just be Social Workers.</p> <p>Independent Professionals should also be acknowledged as able to complete capacity assessments. It should not be the case that only Government staff can complete capacity assessments. It should be widely accepted and acknowledged that specialist services also operate outside of the Government and their knowledge, expertise and decision making should be recognised and respected on the same level as Government staff. It would be entirely inappropriate to reject a capacity assessment and decision from an Independent practitioner on the basis that they do not work directly for the Government. This already happens regularly and should not continue with regards to assessing capacity.</p>
28	<p>Clauses 8 and 9 limitations:</p> <p>Such limitations must not remove the rights of the person(s) legally appointed by the recipient of the care (the person lacking capacity) as their registered enduring/lasting power of attorney (or of such similar title/role as finally to be stated in the act) whilst the recipient had the capacity to make their own decisions. Only the courts</p>

	and legal system should have the power to decide on the removal of any rights given to the registered enduring power of attorney. Under no circumstances whatsoever (apart from imminent danger or when the registered enduring/lasting power of attorney cannot be reasonably contacted), should any organisation or institution have the power to override, in any manner, the wishes declared by the recipient of the care to the appointed and registered enduring/lasting power of attorney, made whilst the recipient had capacity. Likewise, any decision taken by the legally appointed decision-maker (registered enduring/lasting power of attorney) must only be challenged by the courts. The courts having the power to provide an injunction if any action in the short term is deemed questionable.
29	All very agreeable thus far.
30	These are clearly set out and we look forward to the awareness raising and training strategies that will be put in place for health and care professionals to enable them to embed capacity assessments and best interest decision-making into their practices.
31	Improvement to and upgrading the protections afforded to those lacking capacity is welcome.
32	<p>Clause 5 Point 3. 'That a person can only retain information for a short period of time does not mean they are incapable of making a decision' - very important, glad this is clear in the bill</p> <p>Clause 6 Best Interests references the 'decision maker'. Maybe some guidance as to who the 'decision maker' should be would be beneficial (ie. the decision maker being the person delivering the treatment / intervention'</p>
33	<p>Clause 5: "retain information for an appropriate period (subsection (3) then provides what an appropriate period of time is)"</p> <p>-This is unclear. Generally, in assessing capacity the basic principle is that the person can retain the information long enough to arrive a decision. The fact that they then cannot recall the decision they made does not mean that they lack capacity, as long as they consistently arrive at the same decision utilising the same reasoning process. I wonder if this could be worded better?</p> <p>In the England and Wales Act it is worded:          "For the purposes of section 2, a person is unable to make a decision for himself if he is unable—          (b)to retain that information,".</p> <p>It then goes on to include subsection 3 as above.</p> <p>I am also of the opinion that it is essential that clarity is given in legislation and accompanying regulations and Code of Practice as to who will be making assessments of capacity. In my opinion it is ESSENTIAL that it is clear that assessments of capacity do not fall by default to doctors. This is unnecessary and not in the spirit of the legislation which should work on the the principle that capacity assessments are the responsibility of the "decision-maker" and depend on the nature of decisions to be made. There is no reason, for example, why a doctor would be expected to assess capacity for finances and affairs as they are expected to now.</p> <p>At the moment all legal certification of lack of capacity for the purpose of registering EPA or for the purposes of Receivership falls to Medical Practitioners. Apart from anything else, this is impractical and is an unnecessary and inappropriate burden on clinical time, and currently a source of significant delay for relatives etc trying to arrange or implement EPA's etc. It can be a significant struggle for individuals to identify someone to do assessments and provide evidence. GPs generally will not now provide assessments and referrals are therefore often diverted to Old Age Psychiatry practitioners, who do not have the availability to provide the number of assessments which will arise as a result of new legislation, especially as these assessments are "medico-legal" reports rather than clinical work, which doctors are under no obligation to provide.</p> <p>Any legislation should be clear that the responsibility for capacity assessment rests with the appropriate individual at the time.</p> <p>Assumption is also made that Mental Capacity decisions fall, by default, the Mental Health Services. It must be explicit in the legislation that this is not appropriate, to avoid inappropriate referrals to, and increased burden on such Services in what are often non-clinical matters.</p> <p>Clear training processes must be in place to identify appropriate individuals, in sufficient numbers, who can provide capacity assessments for finances, property and affairs, or welfare decisions.</p>

	Clause 6: Needs to include something about best interest decisions also taking into account a persons known wishes or the importance of ascertaining what their wishes would likely have been prior to them losing their mental capacity.
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<b>COMMENTS ON LASTING POWERS OF ATTORNEY – CLAUSES 12 to 20</b>	
<b>Do you have any comments on the proposed new statutory form of power of attorney?</b>	
1.	Extension of the law provided by LPAs is an important addition to the legal framework.
2.	Could "Claudia's Law" (relating to a missing person) be incorporated in some way or passed separately to cover managing a missing persons finances and interests when they are a registered missing person for longer than a certain period?
3.	Clause 14: restraint? This is rarely the best way forward under any circumstances and should only be done at any time under medical supervision/advice. Restraint covers a lot of factors, from locking people indoors, in rooms to extreme cases of restraining people in beds etc. Everyone involved in health care should be trained in appropriate forms of methods to avoid physical or chemical restraint. I understand that there may be times when people have to act in extremis - this needs to be done only when nothing else is possible. Not just when people are "being difficult".
4.	No. In our experience with those who are homeless and insecure accommodation their lives are too chaotic to reach a point of planning instruments like this.
5.	No, all looks relevant
6.	I would prefer if a medical professional was part of the assessment of the lack of capacity and involved in the decision to enact an LPA.
7.	No, I think it is important that the current EPA system is replaced by LPA as soon as practically possible
8.	Will there be financial assistance available for low income persons to enable fairness and equal opportunity to access legally facilitating functions.
9.	Clause 14, it should need to be provable when the Donee believes that the person lacks capacity in a certain instance, as this could take away freedoms of the Donor should be verified by more than just one person. Clause 15, substantial gifts should not be allowed to be political in nature, or out of character for the Donor.
10	<p>We agree that there should be an obligation to notify the next of kin/elected person of the cared-for person when a LPA application is filed as a means to avoid problems that have often occurred in the UK when family members have a lack of awareness as to who may care for their elderly family members. The register of LPA should be efficiently maintained so that family members can determine whether one has been registered and who the attorney is without delay. This would save many issues that families have experienced under the English LPA regime.</p> <p>Please provide further information as to who may access the register and how may a person gain access to it? Presumably the register will not be available to all of the public as it contains sensitive personal data.</p> <p>The capacity of the donee should also be a part of the requirements to be satisfied in order to become a donee is that person is an individual. This is highly relevant for elderly couples who may put their partner as their donee.</p>
11	<p>I have concerns about the bankruptcy requirement on potential LPA's when they are not responsible for assets etc. it feels like an arbitrary requirement.</p> <p>I also don't believe there is enough in place to stop the potential abuse of this system as it currently stands. It implies that the donee is allowed to determine whether the doner is capable of making the decision or not.</p>
12	In agreement
13	Concerns what will happen if someone cannot consent to family members/ parents being their lasting power of attorney. Will control be removed from parental / family control ?
14	Again these sections are very [promising.

15	It is fantastic i love it is very helpful for the manx public and the isle of man. 😊😊😊😊😊😊😊😊😊😊
16	<p>I do not agree with Clause 14. I do not believe someone who is not properly trained and experienced can judge if someone lacks capacity. This leaves vulnerable people open to exploitation where someone can say they believe they lack capacity and act against their wishes when actually they do have capacity. I think you also need to clarify what restraint you are talking about. For example physical, chemical or mechanical restraint? Who will be monitoring this regularly? I would be concerned this would be a safeguarding issue. Use of restraint in ANY form should be prior agreed by an MDT and in a care plan clearly documented and reviewed regularly.</p> <p>Where there is no suitable person to act in this LPA role an Independent Mental Capacity Advocate (IMCA) should be appointed alongside a Best Interests Assessor, as is in the UK. IMCAs are essential to support and advocate on behalf of people who do not have capacity where they have no family members or their family members are deemed to not act in their best interests. Again who will decide and appoint the IMCA? This needs to be regularly reviewed if family are acting in a person's best interests and acted on swiftly.</p> <p>An in-depth DOLS assessment should be submitted and the regularly reviewed by an experienced and qualified DOLS assessor. Again any DOLS should be strictly care planned and agreed by an MDT to be in the person's best interests.</p> <p>Basic training should be available to everyone to educate them on DOLS and what is acceptable and what is not.</p>
17	<p>A problem faced by several of our service users who are donees for health and welfare is that doctors, care home staff and other professionals do not accept the decision-making powers that this role gives them. This causes distress for the donees and means that their loved ones who lack capacity are being denied the individualized decision-making the Act intended to deliver by creating the LPA role.</p> <p>We note that section 28 (C) below gives the Attorney General the authority to deal with how a donee of a lasting power of attorney is exercising their powers. However, neither the Registrar General nor the Attorney General seems to have the responsibility of supporting donees to discharge their duties and this is an omission that ought to be rectified if the benefits of an LPA system are to be maximized.</p> <p>We suggest making it a responsibility of the Registrar General or Attorney General to provide a free helpline to support donees to discharge their duties and deal with disagreements with health and care professionals. This may be included in section 20 or 28.</p> <p>For the system to work effectively, investment must be made in training health and care professionals to understand and work with Lasting Powers of Attorney. This could be incorporated into the Code of Practice and/or the Act's launch and implementation strategy.</p> <p>We suggest that the LPA forms are made as user-friendly as possible so that solicitors are not required for completing it. In our experience, donors are charged large sums by solicitors, even though the registration fee is £82 in England and Wales. Moreover, using a solicitor does not guarantee that the forms are completed accurately. Encouraging potential donors to complete the forms with support from a free national helpline would be the most practical and fair way of establishing this system. This suggestion could be usefully incorporated into the Code of Practice.</p>
18	The new statutory form of power of attorney appears to be much more useful in that it now covers health and welfare as well as property and monetary affairs - so it is much more wide-ranging and provides more protection for the vulnerable individual and more peace of mind to their carer/s.
19	1) This may be covered in the forthcoming D.O.L safeguards section, but will there be specific guidance in the Code of Practice or the DOL s part of the legislation to determine at what point "proportionate restraint" if applied repeatedly becomes formal "deprivation of liberty". I.e, when does restraint become DOL?

	<p>2) In certain cases where there may be remitting and relapsing Mental Illness, such as Psychosis or Bipolar Disorder, patients often lose their confidence and can become vulnerable to coercive control ( e.g. by a partner or parent), even when fully well. The Commission would like to see strong safeguards in place, which are not dependent on the donor having to instigate a potentially daunting process, where they can regain full control of their affairs when they are well.</p>
20	<p>The new statutory forms are of great relevance to the title register and to the Land Registry. The Land Registration Act 1982 (s6 and ss55-56) and the Land Registry Rules 2000 (Rule 103) already make provision for execution of documents of transfer by donees under powers of attorney and for the appointment by the Land Commissioner of a guardian of those lacking capacity on a reference from the Land Registrar.</p> <p>The Land Commissioner is a judicial office created by the Land Registration Act 1982 enjoying the same powers as a judge of the High Court by virtue of section 2 of the Land Registration Act but constituted under a separate jurisdiction.</p> <p>It is recommended that the Department familiarise themselves with the detailed operation of these provisions of the Land Registration Act to ensure that any responsibilities and duties created under the capacity act for the benefit of donors and donees are extended where relevant to the Land Registrar and the Land Commissioner.</p> <p>It is recommended that thought be given to creating an obligation to register a caution over any registered land owned by a party coming to lack capacity in order to prevent unauthorised dealing with their property. For example, under rule 93 and 94 of the Land Registry Rules 2000 (in the case of Bankruptcies) and under rule 68 (Trustee owners) there is already a facility to register an inhibition preventing dealing with land by the registered legal owner without notice being served on a named party. Generally these are in a form such as: "Except by order of the Registrar no disposition by the registered owner is to be registered without the consent of [named appropriate authority]".</p> <p>HM Land Registry (in England and Wales) have a system of registering the need to notify donees prior to completion of a transaction. Such a system would serve great benefit in protecting the real estate of a party losing capacity but also would bring great benefit to any prospective purchaser as it would enable them to gain a true picture of with whom they need to contract in order to acquire registered land. This goes to the heart of the system of Land Registry in the Isle of Man.</p>
21	<p>'Unlike an EPA, a LPA can extend to personal welfare matters as well as to property and affairs. By making an LPA, an individual (the donor) confers on another individual or individuals (donee(s)) authority to make decisions about the donor's personal welfare and/or property and affairs or specified matters concerning those areas.'</p> <p>I don't know if this is clear or would be to colleagues working within this framework. From working within the MCA 2005 there were two clear separate area's for LPA's - Health and Welfare Finances, Property and affairs</p>
22	<p>Clause 14: This is unclear and seems to mainly only be referring in detail to restraint, where in reality the health and welfare aspects of LPA are more likely in practice to involve decision making regarding medical treatments or welfare decisions such as care placements etc.</p> <p>In general, this section of the consultation keeps referring to "personal welfare " decisions and this may be misleading. It would be much clearer to refer to "HEALTH and WELFARE" to clarify the powers of the donee.</p> <p>There need to be clear pathways in the LPA process to resolve areas of conflict which may arise between LPA donees and those delivering health and welfare decisions if there is disagreement on what is in a persons best interest.</p> <p>I note that the equivalent section in the 2005 Capacity Act refers to : "But subsection (7)(c)—</p>

	<p>(a)does not authorise the giving or refusing of consent to the carrying out or continuation of life-sustaining treatment, unless the instrument contains express provision to that effect, and (b)is subject to any conditions or restrictions in the instrument."</p> <p>Decisions surrounding life -sustaining treatment and end of life care are a likley area of disagreement and guidelines and processes here need to be very clear and explicit. I presume these will be written into a detailed and comprehensive Code of Practice to accompany any legislation.</p>
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<b>COMMENTS ON THE GENERAL POWERS OF THE COURT AND APPOINTMENT OF DELEGATES? – CLAUSES 21 to 27</b> <b>Do you have any comments on the proposed powers of the Court or delegates appointed by the Court?</b>	
1.	very important!!!! ..... it would not be acceptable for a delegate to carry on making substitute decisions when the person concerned had in fact recovered
2.	My only comment is that I have the power to appoint who I want as my "delegate". My Civil Partner and I have the current Power of Attorney, naming each other as our appointed Representative/delegate/attorney. We would want this to continue without any problems. We have known each other for 60+ years and know each others wishes.
3.	What are the checks on the power of the court to make decisions ? Who can be an advocate to act on behalf of the person lacking capacity if there is a question as to the fairness of the decisions being made for them?
4.	Will the delegates have their situation regularly reviewed by the Court? This could be an additional safeguard. In my experience the reality of life is a lot more messy than the orderliness of Court proceedings. Sometimes a vulnerable person will have fluctuating and unclear capacity but decisions need to be made within a timescale that does not allow for proper assessment or Court proceedings. Delays can cause a deterioration in a person's circumstances. I don't offer any solution to thos problem, merely a comment.
5.	Often a lack of POA is due to not expecting a loss of capacity etc. It is not clear that if, in the first instance, family members or NOK are considered a delegate prior to court/court identified delegates/trust.
6.	No this seems comprehensive
7.	Opportunity to Challenge?
8.	Clause 26 (1) could cause problems where there is "fluctuating capacity" and takes a decision when the individual had a lucid moment and might have determined differently. A decision taken by the delegate in good faith must be honoured and the delegate protected from any adverse consequences.
9.	What happens where there is a disagreement between 2 delegate? How is the review of capacity undertaken and how are delegates supported to ease back on control?
10	Will the courts appoint an independent person? The person delegated should not be a paid employee of the Government or private facility involved in the care of the vulnerable.
11	Nope, sounds good
12	Where possible priorities of use of delegates come from family / parents. Parents / family members must have funding provided to ensure they have fair access to have their own legal representation in court if needed especially if not eligible for legal aid.
13	It is very helpful and important.😊😊😊😊😊😊😊😊
14	If the Court is to decide whether a person lacks capacity or not a Speech and Language Therapist will be essential to aid in this decision and facilitate effective communication. Although Courts can make many decisions, they do not specialise in communication and as a large part of assessing capacity relies on communication a specialist is required. Courts do not know the different ways to facilitate communication which are not verbal.



	<p>Delegates appointed by the Court should be trained Independent Mental Capacity Advocates (IMCA) who should be regulated and scrutinised regularly.</p> <p>There is a large evidence base for Speech and Language Therapists to be used within capacity assessments. Please do look into this. I have included a recent paper for your review.</p> <p><a href="https://onlinelibrary.wiley.com/doi/10.1111/1460-6984.12585">https://onlinelibrary.wiley.com/doi/10.1111/1460-6984.12585</a></p> <p>Title: Giving voice to people with communication disabilities during mental capacity assessments.</p>
15	Strikes a good balance.
16	What checks will be carried on the delegates to ensure they are fit & proper for carrying out the decisions they will take and will the checks be carried out at regular intervals to ensure that the delegate is acting correctly?
17	<p>At present the Land Registration Act provides a platform for the protection of property owned by parties who have lost capacity. This regime is exercised by the Land Registrar and the Land Commissioner.</p> <p>The Land Commissioner is a judicial office created by the Land Registration Act 1982 enjoying the same powers as a judge of the High Court by virtue of section 2 of the Land Registration Act but constituted under a separate jurisdiction. The present Land Commissioner is Deemster Gough BUT in accordance with section 2 of the Land Registration Act there is no requirement for the officer appointed as Land Commissioner to be a Deemster.</p> <p>It is recommended that the Department familiarise itself with the detailed operation of those provisions of the Land Registration Act dealing with mental capacity to ensure that any responsibilities and duties created under the capacity act for the benefit of donors and donees are extended where relevant to the Land Registrar and the Land Commissioner. In the absence of this there will appear to be two separate regimes for protecting land of donors where that land is registered.</p> <p>The Land Registrar is happy to provide any guidance the Department requires. The office of the Land Commissioner is operated separately from the Land Registry and the department would have to contact the Land Commissioner to address any concerns he may have directly with him. I have not discussed this consultation with Deemster Gough and do not represent him or speak for him.</p>
18	<p>Appointment of an LPA donee (or delegate) will consideration if two or more donee's or delegates are identified, if their decisions are going to be in severance or jointly? Michelle Norman explained this well at one of our meetings.</p> <p>Financial capacity assessments for REGISTERING of an LPA . Currently a medical certificate is required to register a POA. GP's are largely now deciding as partners that they will no longer complete capacity assessments. Dr Jagus / OPMHS medics receive Category 2 requests from Advocates, however I am aware that he is considering that financial assessments should NOT require a medic. I do think however that it would be unfair for this responsibility to fall on the involved nurse/CMHP/Social Worker with regards to registering a LPA. Perhaps consideration of training someone within the department to become proficient and competent to complete the financial assessments would be prudent with the developing of the Act.</p>
19	"The role of a delegate is proposed to replace the role of a court appointed receiver under s.103 of the Mental Health Act 1998."- This seems highly appropriate.

**COMMENTS ON THE ATTORNEY GENERAL – CLAUSES 28 to 32**
**Do you have any comments on the proposed functions of the Attorney General under the Bill?**

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| 1. | Attorney General has a conflict, he should be excluded from any matter regarding capacity. AG acts for the IOM Government not the public. It should be an independent party. |
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2.	Opportunity to Challenge?
3.	Will the vulnerable person be allocated an Independent legal advisor or independent guardian support
4.	Decisions made for an individual should not be taken out by a sole person, more than one person needs to be involved in best interests, as well as where possible brining the person with limited capacity into the discussion
5.	This is fine assuming that data protection laws will continue to force the AG to destroy records at a time they are no longer needed.
6.	In agreement.
7.	They are being very helpful. And understandable. 😊😊😊😊😊
8.	I don't understand this so can't make comment.
9.	See previous comment regarding the Attorney General or Registrar General being responsible for supporting donees to discharge their duties.
10	<p>The role of the Attorney General as public guardian is satisfactory and appropriate. It may be worth ensuring that the independence of the officer performing the functions of public guardian is entirely independent and free from political influence.</p> <p>I make absolutely no suggestion that the AGC is subject to political influence and indeed I am certain it is not. As a matter of policy the creation of an independent office of public guardian may also be considered. The Land Registry has no position on this point and this comment is provided for assistance only.</p>

<b>COMMENTS ON ADVANCE DECISIONS TO REFUSE TREATMENT – CLAUSES 33 to 35</b>	
<b>Do you have any comments on the proposed provisions regarding advance decisions to refuse treatment?</b>	
1.	If a person with no insight into their mental illness made an advanced decision, when they were deemed to have capacity, to have no treatment how would that work? Surely insight is needed to make an advanced decision when dealing with chronic enduring mental illness like paranoid schizophrenia?
2.	A comment on concern for some of the more isolated and vulnerable people that we see. The complex of mental and physical ill health, frequently exacerbated by trauma both present and historical, puts people in a very vulnerable position when thinking about their health and end of life care. I would have concerns that people would feel the need to refuse treatment or implement advance decisions because of pre-existing (sometimes for decades) problems and pain, rather than what they might do given proper help. The way that this dynamic reacts with capacity is obviously complex and debatable. I do not think there are easy solutions but these dynamics do need to be considered.
3.	Children under 16 must not be automatically excluded from making decisions about their care. Gillick Competence should be used, see <i>Gillick v West Norfolk and Wisbech AHA [1986]</i> .
4.	Are advance decisions to be recorded in written form and included within the parameters of an individual poa?
5.	Am pleased that advanced decision is being taken into account; we just need all island documentation to that effect. Suggest RESPECT documentation.
6.	This seems to state that an advanced decision can be over-ridden by the donee if the person then loses capacity. I do not agree with this- the clearly expressed wishes of the person should stand and not be overridden. This would also put doctors in a very difficult position if there was a clear advanced decision, but the donee wished to proceed against the advanced decision.
7.	ensuring that the decision around advanced decision is properly informed.

8.	Who will gain, assess and log advanced decisions for the vulnerable, will persons on low income be able to access free advice and service to ensure they have opportunity to progress advanced decisions if they have no family or donee in place?
9.	Advance decisions being made should be held as the first part of decision making. And even in cases should liaise with the person in question to try and affirm any choices made - especially in end of life decisions.
10	How will advance decision records be kept and who may access them other than the donee?
11	<p>'Also, if the person to whom the advance decision applies has acted in a way that is clearly inconsistent with the advance decision then it becomes invalid'</p> <p>This is very important and I am glad this is in here.</p>
12	In agreement
13	Family / parents of adults who have close knowledge/ care of the person, their opinions must be taken into account.
14	They should not refuse any treatment whatsoever they should let treatments carry on if people need treatment. 😊😊😊😊😊😊😊😊
15	Excellent.
16	These are essential but should be transported and clearly documented on ALL medical records. There should be a flagging system on all medical records to document it is in place. I understand medical services do not all share the same electronic notes systems therefore there should be an ability for audits to be completed to ensure anyone with an advanced decision has this consistently across their records.
17	Very well handled.
18	<p>1. "An advance decision will not apply to life-sustaining treatment unless it is verified by a statement confirming that the decision is to apply to that treatment even if life is at risk" – This clause seems to be missing from the body of the Bill even though it is included in the Explanatory Memorandum (pg viii). This statement has however been included within the section on Advance Consent but what that means in practice is not entirely clear. Does it mean the individual consents to high-risk life sustaining treatments? Clarity that “consent to treatment” does not mean “requesting a treatment” may be required in the Code of Practice.</p> <p>2. The Bill states that an individual needs to be 18 to complete and LPA but 16 to complete an ADRT. Is there a reason for this difference?</p> <p>3. One of the challenges that the Mental Capacity Act in England and Wales has faced with regards to Advance Decisions is the lack of a standard form that may be completed by a person. As a result, health and care professionals are not able to easily recognise and therefore respect an Advance Decision which can cause significant distress to an individual wishing to plan ahead.</p> <p>Compassion in Dying has supported over 56,000 people to plan ahead and we are the leading provider of Advance Decisions in the UK. The NHS website links to our forms which we open source to anyone wishing to adopt them for their use. For example, we worked with the Jersey Government when they introduced their new capacity legislation and their official Advance Decision template and guidance notes is based on our form. Please do get in touch if you would like to discuss this further.</p> <p>Guidance notes -  <a href="https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/ID%20Making%20an%20Advance%20Decision%20to%20Refuse%20Treatment%20(ADRT)%20-Guidance%20Notes.pdf">https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/ID%20Making%20an%20Advance%20Decision%20to%20Refuse%20Treatment%20(ADRT)%20-Guidance%20Notes.pdf</a> (page 2 acknowledges Compassion in Dying)</p>

	<p>Form  <a href="https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/F%20Advance%20Decision%20to%20Refuse%20Treatment%20ADRT%20Form%2020180928%20TF.pdf">https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/F%20Advance%20Decision%20to%20Refuse%20Treatment%20ADRT%20Form%2020180928%20TF.pdf</a></p> <p>4. It would be very helpful if Code of Practice could provide clarity on who can or should assess capacity and that this should not be a chargeable service.</p> <p>5. We strongly recommend that the Code of Practice include a clear emphasis on professionals’ responsibility to have a basic understanding of the core rights and responsibilities under the Act for their patients and themselves, and an understanding of where to go for more information on the Act. Misinformation about Advance Decisions can lead not only to distressed individuals but also wrongful, unlawful treatment as in the cases of Brenda Grant [2017] (who was given life prolonging treatment against her wishes for 22 months) and Jillian Rushton [2018] (whose clearly expressed treatment wishes were disregarded, resulting in her being provided with the very treatment she had taken steps to refuse).</p> <p>6. The Code of Practice should clarify professionals’ responsibility to record Advance Decisions. If there are no systems in place to efficiently share a person’s Advance Decision with those making treatment decisions, the benefits of the capacity legislation will not be realised. An option worth exploring is to establish a central register of Advance Decisions (similar to the organ donation register and the register for Lasting Powers of Attorney), thereby resolving some of the difficulties we see in them being accessed across healthcare settings.</p> <p>7. With regards to the validity of an Advance Decision when there is an LPA in place (section 35 (2) (b) – it may be useful to know that many people wish to have the reassurance that their donee will ensure that their Advance Decision is known about and respected. To do this, donors include an instruction in the LPA stating that “the donee must follow my Advance Decision.” It will be useful to clarify in the Code of Practice and in your training and implementation strategy that these two instruments for advance care planning work well together.</p> <p>8. Clarity with regards to how Advance Decisions to Refuse Treatment and Advance Consent work together would be useful to include in the Code of Practice. For example, we imagine an individual would need both forms if they wished to consent to pain relief but refuse artificial nutrition and hydration if they were to suffer a brain injury and lose capacity to make their own decisions.</p>
19	<p>If treatment can be withheld whilst it is ascertained whether there is a valid &amp; applicable qualifying advance refusal, would this also be applied to an emergency i.e. life or death situation?</p> <p>My son has been diagnosed with schizophrenia and has already made one attempt on his life. His mental health fluctuates from near normal to psychotic and suicidal and his memory is very badly affected.</p> <p>If he lodged an advance decision 'to not be resuscitated' when he was feeling down his decision could change when his mental health improved and his attitude might change, but he would not remember the original decision he made and so would not know to amend the advance decision.</p> <p>What safeguards would be in place for a situation like this and how would emergency room staff know what decision to make?</p>
20	<p>The Commission feels it would be an opportunity now to create a place in “cyberspace” where valid Advance Directives could be logged, that can be accessed by professionals anywhere with the use of appropriate security. This would ensure that Advance Directives are known about when this information is needed and decisions are not dependent on hearsay or medical notes elsewhere etc.</p>
21	<p>Advance decision to refuse treatment 'An advance decision can only be made by a person who is at least 16 years of age with mental capacity to do so.' - Who deems this person to have the mental capacity to do so?</p> <p>Clause 34 discusses what would make an advance decision invalid, and Clause 35 states that an advance decision must be both valid and applicable - HOW is this identified? In the MCA 2005 Advance decisions are written down (or spoken and documented), and signed, with a witness. My big concern with this is who deems the person to be</p>

	<p>making the advance decision as having capacity, and not to be suffering from an impairment of or disturbance of the mind or brain?</p> <p>From all accounts, an advance decision could be documented by someone who is mentally unwell or lacking capacity to make this decision, and witnessed by a layman.</p> <p>I personally have supported a patient who was NOT mentally unwell to complete an Advance Directive, which was also counter-signed by OPMHS Psychiatrist after face to face assessment, and also by GP. I hope that this would give the treating medic in an acute physical setting the confidence to deliver the Advance Directive as wished by the patient. I have concerns that without these measures the treating medic might question the validity of an advance decision, or, the advance decision might have been made by someone who is not making a decision with a sound mind.</p>
22	<p>"An advance decision can only be made by a person who is at least 16 years of age with mental capacity to do so.": There needs to be robust processes in this area to ensure that Advance Decisions are valid. The requirement of possessing capacity to make draw up an Advance Decision needs to be ensured. At present it is possible for a person to merely draw up an informal handwritten advanced decision. I understand that there is no requirement for this to be witnessed, and there are no processes for ensuring that the person had capacity at the time that they drew up the document. This can leave practitioners in difficult circumstances when making treatment decisions where there is such a document in place as it can be unclear as to the validity of the document,.</p> <p>To my mind, because of the potential gravity of the decisions that may be in question, it should be essential that Advanced directives are formalised legally drawn up documents. They should be formally witnessed, and have legal oversight to ensure they are valid, clear and unambiguous. It also should be essential that there is some sort of documented confirmation that the person had mental capacity at the time of making the directive. At present it seems that this is not necessary, therefore casting doubt on the reliability and credibility of any document.</p>

<b>COMMENTS ON THE SUPPLEMENTAL CLAUSES – CLAUSES 39 to 43</b>	
<b>Do you have any comments on the proposed provisions of the Capacity Bill regarding excluded decisions, research and the offences of ill-treatment and neglect?</b>	
1.	It should be regulated and have a proper complaints procedure. The current DHSC complaints procedure is unregulated and not fit for purpose.
2.	Does ill treatment include all forms of abuse and coercion including psychological and financial as well as physical?
3.	Ill-treatment or neglect should be treated as any other Criminal Offence would be. The term "physical abuse" is often applied in these cases - and in many of these cases it is not abuse it is assault.
4.	How would this have affected /altered Coronavirus vaccination?
5.	will some form of learning be available to delegates so ensure they fully understand what they are signing to undertake?
6.	In respect of psychiatric treatment, talking and non-medical interventions should be made long before the use of drugs or medications are used on the person in question. this is to avoid instances of being drug addled and unable to make capacity decisions, when if not drugged the person would actually be in capacity.
7.	All sounds good
8.	In agreement
9.	If you can't consent to a marriage or a civil partnership, you surely can't consent to a sexual relationship?
10	I think that neglect is absolutely awful for animals and people. 😊😊😊😊😊
11	Good. Well overdue

12	The term 'intrusive research' is not grounded here. Subsection 7 allows for DHSC to make regulations which define the term, but it is no clear that it is DHSC who would satisfy this role. If responsibility for research was located elsewhere, this might need amending so that the regulation making powers are correctly placed.
13	There is an ideal opportunity here to consider one piece of overarching legislation which unites the Mental Health Act and mental capacity legislation also including clear legislation regarding deprivation of liberty. (DOLS) Certainly, mental capacity legislation must include clear deprivation of liberty safeguards rather than it being a separate piece of legislation as in England. Merging this with Mental health Law would also result in clear processes for managing patients. It would give clarity as to when Mental Capacity principles would apply, and when Mental health Act principles would apply.

<b>COMMENTS ON THE CODES OF PRACTICE – CLAUSES 44 to 45</b> <b>Do you have any comments regarding the provisions proposed for the Code of Practice?</b>	
1.	All Codes of Practice should have public consultation and require Tynwald Approval.
2.	How long is this going to take?
3.	The summary of the Bill included in this consultation is useful. But with another consultation planned for the codes of practice, what's the point of this one? The 2020 consultation showed overwhelming support. Please get on and enact it!
4.	Will the code of practice be presented for public consultation?
5.	No comments for the Code of Practice. However, we note with concern that under Schedule 6, the entirety of the Powers of Attorney Act 1983 (1983 Act) is to be repealed without any apparent new provisions being proposed to replace it. The 1983 Act includes general rules for ordinary powers of attorney which are used extensively by individuals and entities to conduct general business. In addition, the repeal of the 1983 Act will do away with powers of attorney surviving bankruptcy and insolvency which is often key where there is secured lending. The rules governing ordinary powers of attorney are necessary to enable the continued use of these powers of attorney in day to day transactions and their repeal will result in significantly less clarity in this area. The appropriate provisions of the 1983 Act should either be retained or simultaneously replaced.
6.	In agreement.
7.	I think the code of practice will be extremely helpful. So i think people should use it. 😊😊😊😊😊😊
8.	We look forward to sharing our experiences with LPAs, Advance Decisions and best interest decision making by contributing to the development of the Code of Practice.
9.	I agree that a thorough and readable Code of Practice is essential to those who will be implementing the Act. The MCA Code of Practice is an excellent example of how one can support the Act from the Understanding of the principles, assessments, best interests and the legal context.

## APPENDIX 2 – ‘HARD TO REACH’ REPORT SUMMARY

### We Asked

The purpose of the consultation was to seek views on the proposed capacity legislation from people who would not be able to contribute through the usual channels.

Due to the pandemic it was not possible to speak to people directly, so instead we tried to harness the skills, knowledge, and direct access of carers to support conversations about capacity with people they care for.

### You Said

People kindly told us about their own experiences of making choices both inside and outside of care settings. They also offered a range of views about how support should be provided and by whom. Respondents told us about decisions that were most important to them, and how it felt when choices were taken away.

Those supporting the process indicated how much assistance was provided in each case, and what their relationship was to the person.

### We Did

The project welcomed all feedback and the Department considered each comment made in response to the survey.

The responses were analysed for key themes, for alignment with the policy position, and for any points which might be relevant to the draft bill or its implementation.

## 1. Background

The Capacity Bill will govern decision-making for individuals who may lack or have lost the capacity to make decisions for themselves. It will provide assurance that people will be supported to make a decision for themselves wherever possible, and will have decisions made in their best interests where it is not.

In the autumn of last year the Department of Health and Social Care (“the Department”) ran an eight week public consultation. The purpose of this was to seek views and, where relevant, evidence to support those views on the policies that would shape the Island’s new capacity laws.

Overall, there was strong support of the need for a modern and clear legal framework for people who may have lost the capacity to make decisions for themselves, and a general consensus as to what the overarching capacity principles should be, in the new Capacity Act.

Having carefully considered and analysed the responses that were received, the Department published on the Government’s Consultation webpage the [“Summary of Consultation Responses on Capacity Policy Principles”](#)

The responses received from the autumn consultation, have been used to inform and shape the Capacity Bill 2021. A consultation on the draft Capacity Bill concluded on the 8th of April 2021.

## 2. Report Format

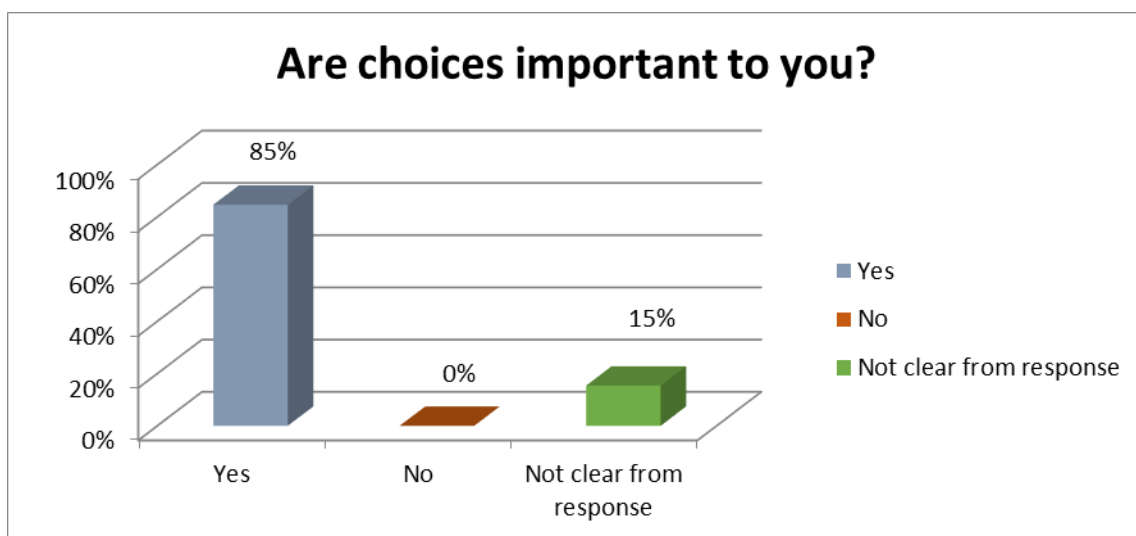
The consultation was based on informal conversations between the person being consulted, and a known person (typically a relative or carer) who supported the process. Questions were not fixed, but there were some suggestions offered as starting points. Due to the more limited reach of this report and some of the challenges in terms of access and communication, the following should not be understood as representing all of those affected in a statistical sense. However, the views offered here are those of people whose lives are impacted by capacity; voices would not have been heard at all without an adapted approach.

The responses received were analysed for common themes, and any points of disagreement. A narrative is offered which explores how widely held these views were amongst respondents, and the strength of feeling behind them. Charts are included to illustrate some key points, but it is important to note that the questions presented here were not explicitly asked, and the information is based on an interpretation of the written summaries of conversations. The text included is based on both the number and specific content of responses, and offers a better reflection of views held than numerical data is capable of in the circumstances.

At the end of each section findings are considered in relation to the proposed bill. At the end of the report is a summary.

## 3. The Responses

### Having choices and making decisions is important to people.



The majority of respondents were clear that the ability to make choices was important to them. The responses where this was less clear were entered on behalf of a service rather than individuals which may explain why this differs from individual responses. No response suggested that the ability to make choices was unimportant.



Several respondents told us about how they have felt when they have been unable to make choices. The most frequent comments suggested people would feel sad or angry if they were unable to make choices for themselves.

All responses on this point stressed the importance of being able to make their own choices, and the strength of feeling was also notable. This suggests strong support for the principle of self-determination enshrined in the current Capacity Bill.

**People have preferences about who should be involved in decisions. Family are seen as particularly important. Involving a range of people is also important.**

Most respondents acknowledged that they sometimes need help to make decisions, or may require help in the future.

There were several sources of support identified, but in order of popularity they were:

- 1) A family member (often specified) – The most popular response, and sometimes indicated as the most important to include
- 2) Care/Support Staff – Featured almost as frequently as family, but prioritised less often
- 3) Friends/a partner/other healthcare professional – Mentioned less often, but in some cases felt to be very important
- 4) Other – There were some single responses specifying a particular person or role

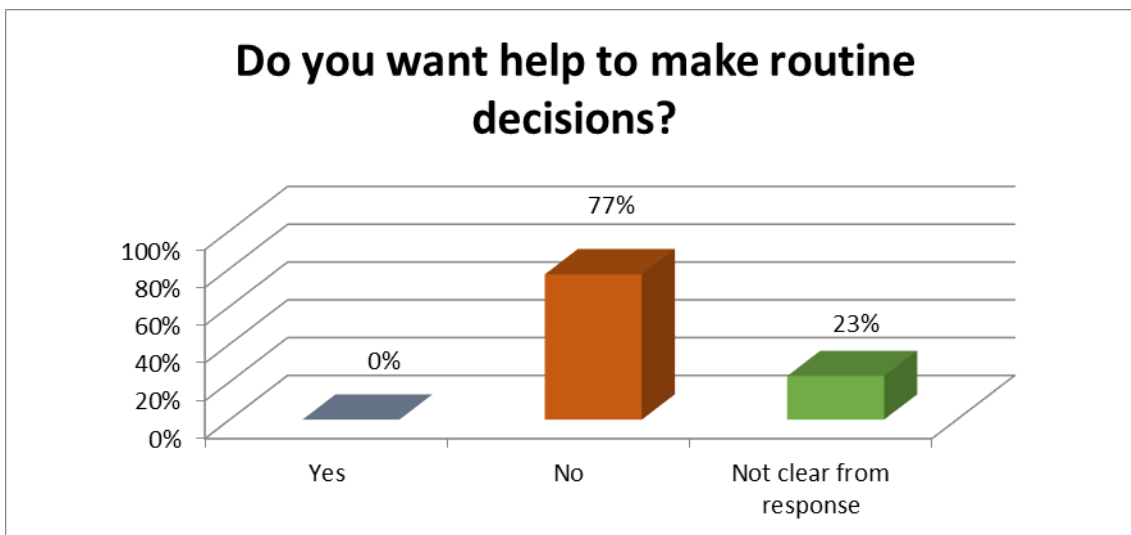
The list above only tells part of the story. The majority of responses identified two or more sources of support. Whilst the single most important contributor for some people was a family member, most respondents told us that they would also like to see different people involved.

A final point worth considering is that whilst more than 70% of people thought the inclusion of paid care staff was important, no one suggested that only staff should be consulted.

The Capacity Bill promotes inviting input from a range of individuals, it allows for key people (such as family members) to be granted certain decision making powers when this is what the individual wishes, and it will provide safeguards for people who have no one to advocate for them in relation to certain decisions. The responses here seem to support each of these.

**People often resist or refuse help when it is not needed.**

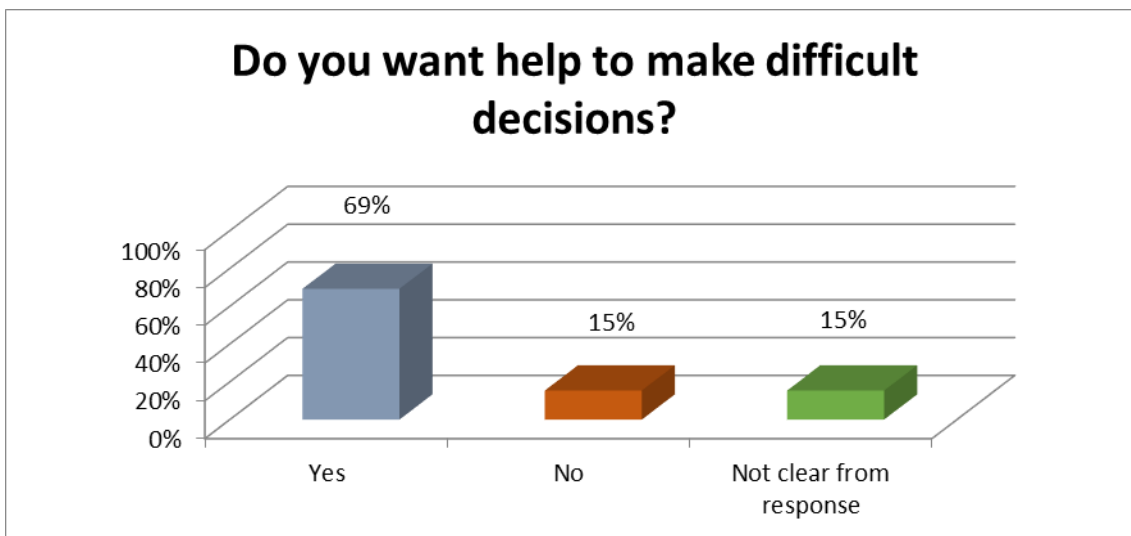
The majority of respondents did not want any help making decisions they felt confident to make for themselves, and such input was often viewed as unwelcome interference. Some people offered examples of paid care staff or family members involving themselves when input was not wanted, and in each case it was viewed as a very negative experience.



Some people offered examples of paid care staff or family members involving themselves when their input was not welcome, and in each case it was viewed as a very negative experience.

**People are more accepting of help when it comes to difficult decisions.**

When compared to simple decisions, the pattern was broadly reversed for more difficult decisions, with the majority of respondents welcoming input, although some people suggested they would still reject or resist help.



It should be noted that those who rejected help with difficult decisions did accept that others may have to decide if they were completely unable to do so for themselves.

**There were some particularly strong responses in relation to unwise decisions, but it would be wrong to present this as simply for against.**

For around half of the respondents, the unwise decisions they make were thought to be amongst the most important for their happiness. Most people were able to recognise certain decisions as unwise, which suggested reasonable insight.

There were also some strong views offered about unwise decisions that people did not approve of, with most examples offered relating to things that were illegal or very unhealthy.

There were no responses calling for severe restrictions on the ability to make unwise decisions.

The Capacity Bill will promote people being free to make their own decisions where possible, and will require support to be offered when it is needed. Unwise decisions will not be viewed as evidence of someone's inability to make a decision, and people will still be able to make unwise decisions when they have the capacity to do so.

### **People prioritise decisions differently.**

Almost every response included details of the type of choices that were particularly important to the respondent. It is worth noting that there was very little overlap, suggesting that every individual has their own set of priorities.

Examples offered included decisions about friends and activities, food and drink, choice of clothing, or whether or not to receive the COVID 19 vaccination.

This suggests that the impact of restricting a certain decisions would affect each person differently. The bill requires consideration to be given to the impact restricting decisions would have in relation to the individual which will hopefully account for this.

## **4. Conclusion**

Overall, the responses appear to suggest that both the policy principles and the draft bill will address the needs and preferences of those who can sometimes struggle to make certain decisions.

There were no themes identified that would contradict the policy principles, or anything found in the draft bill.

On this basis it is believed that the draft bill would be welcomed by those who responded.

# **END OF REPORT**