

ARTICLE

# Anything Goes? Analyzing Varied Understandings of Assent

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## Abstract

Assent to medical research or treatment may be an intuitively attractive way to address the area between incapacity and capacity that might otherwise be subject to a best interests assessment. Assent has become a widely disseminated concept in law, research, and clinical ethics, but little conceptual work on assent has so far occurred. An exploration of use of assent in treatment and research in children and people with dementia suggests that at least five claims are made on behalf of assent. Since at least some of these may lead to tensions with others, assent requires firmer conceptual underpinning. Whether assent remains primarily a local approach to research in children in the United States, where it appears to fit with legal background conditions, or develops its promise to overturn the dominant, binary, approach to (in)capacity will depend on the strength of future philosophical work to improve the theoretical foundations to assent.

**Keywords:** assent; children; dementia; capacity; research ethics; clinical ethics

## Introduction

Assent is described by the Ethics Working Group of the Confederation of European Specialists in Paediatrics as “a child’s agreement to medical procedures in circumstances where he or she is not legally authorised or lacks sufficient understanding for giving consent competently.”<sup>1</sup> It has been claimed that, by seeking agreement, assent fosters autonomy and moral growth, and improves decision-making skills.<sup>2</sup> Although assent is most prominent in pediatric bioethics, it is advocated in numerous contexts, both legal and ethical, where we cannot effectively seek consent. The idea of seeking assent in these circumstances may be intuitively attractive to many, yet the concept of assent lacks detail and might be interpreted in very different ways.

Receiving assent from children for their participation in research is legally recognized in a number of jurisdictions. The United Kingdom (UK) research regulator, the Health Research Authority,<sup>3</sup> augments UK<sup>4</sup> and European Union (EU) law,<sup>5</sup> and all research involving children must seek assent. In bioethics, assent is increasingly proposed to advance a liberating agenda to those who ostensibly lack the ability, legal or otherwise, to make autonomous choices. Although originating in research, assent is advocated in the treatment of both children and people with dementia. Within research, assent has also been advocated in diverse populations including people with disorders of consciousness and animals used in research. In this article, after exploring the origins of assent, I ask how assent is conceived in the treatment of, and research with, both children and people with dementia. A variety of justifications are suggested for assent. These include the contention that assent will benefit under-researched groups, enhance individual autonomy, educate in decision-making, allow paternalistic protection of the welfare, and prevent or reduce harm. All of these justifications are found in children’s research and almost all in children’s treatment, but fewer in dementia treatment and research. In some interpretations, these justifications may be consistent. Yet depending on their relative weight and interpretation they may suggest contradictory inclinations, and I question their ability to provide a footing for a consistent use of

assent. Since assent is sometimes claimed to be a moral augmentation of the law,<sup>6</sup> a more rational approach to assent may be to consider the background legal conditions in particular jurisdictions or national contexts. For example, assent in children may have a role to play in the United States, where it may answer what some critics perceive as a national deficit in children's rights.<sup>7,8</sup> If this seems too parochial an approach, a grander ambition may come from making a common cause between the use of assent and the international agenda to reconceive decision-making in line with the approach advocated in the U.N. Convention on the Rights of Persons with Disabilities. Assent may currently lack a firm grounding that would promote consistent use, yet the promise of assent in offering recognition to members of otherwise marginalized and misused populations remains intriguing. I conclude by calling for the development of firmer theoretical foundations for assent to help meet this challenge.

Before proceeding I should note that my discussion inevitably considers the inverse of assent, that is "dissent." While the nature of dissent potentially remains as ambiguous as assent,<sup>9</sup> I do not delve deeply into the concept of dissent to avoid hopelessly lengthening this discussion, instead considering it as the simple opposite of assent. Secondly, it is pertinent to address potential terminological misunderstandings around the terms "capacity" and "competence," which are often used to describe decision-making ability. "Capacity" and "competence" have distinctive philosophical meanings.<sup>10</sup> Moreover, they have different meanings in different legal jurisdictions.<sup>11</sup> For example, English legal parlance uses the term "capacity" in the civil law only. Therein, "capacity" generally pertains to adults and encompasses the decision-specific test found in the Mental Capacity Act 2005. "Competence," meanwhile, relates to a test of children's decision-making maturity found in the common law. In the United States "competence" is employed within legal terminology in both civil and criminal law,<sup>12</sup> while "capacity" is reserved as a bioethical and medical concept.<sup>13</sup> This paper generally uses the terms capacity/incapacity to describe the ability/inability to make decisions. As my focus is on decisions within medical research and treatment, I include disease, immaturity, and lack of legal empowerment as reasons a person may lack capacity. Thus, by incapacitated individuals, I include children (who may well have unimpaired reasoning but face legal and other barriers to their decision-making) as well as adults with an acquired or congenital inability to make decisions.

### Binary Approaches to Incapacity and the Emergence of Assent

Classic approaches to decision-making in bioethics take a binary approach hinging on an individual's ability to make a decision. Those with decision-making capacity exercise their autonomy. Those without capacity have a decision made on their behalf, according to their best interests (howsoever these are constituted—although, from the perspective of contemporary English law, "best interests" do include a consideration of the views and wishes of the child or adult concerned, and thus arguably move toward the middle ground where these views and wishes can be ascertained). Yet this binary approach risks doing a disservice to those who have some decision-making ability but lack the ability for independent decision-making at all times, either due to immaturity (such as children), fluctuating capacity (such as adults with certain disorders or diseases) or where complex communication is impossible (adults with some disorders of consciousness or sentient animals). Depending on the degree we prioritize a liberal commitment to respecting autonomy in healthcare (and I shall not unpack this challenging question here), this entails finding some way of addressing the perceptions, preferences, and choices of incapacitated people. Various remedies exist, that may be more or less acceptable in one group or another. These include: following antecedent instructions drawn up by the individual; allowing family members to decide on a relative's behalf or; calling on an experienced professional to make a substituted decision based on the individual's likely wish. Whatever their merits, these solutions share a common weakness. Even when exercised in good faith, they fail to address the individual's own current perceptions, and thus are mere approximations of choice. Problems addressing the needs of these groups are evident in clinical practice<sup>14,15</sup> and are the topic of legal research.<sup>16</sup>

Assent first emerged as a bioethical concept in the 1977 report by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research published in the United States<sup>17</sup> (hereafter: "National Commission report"). It seems likely that its conceptual roots lie in U.S. tort law, where informed consent was at one time considered to comprise "awareness" and "assent."<sup>18</sup> Assent was

**Table 1.** First Appearances of Different Applications of Assent

Date	Where first appeared	Group	Application
1977	National Commission Report <sup>28</sup>	Children	Research
1983	Article by Leikin <sup>29</sup>	Children	Treatment
1995	Proposed guideline by Keyserling et al. <sup>30</sup>	Adults (Dementia)	Research
2000	Declaration of Helsinki <sup>31</sup>	Adult and children (“incompetents”)	Research
2004	Article by Molinari et al. <sup>32</sup>	Adults (Dementia)	Treatment
2012	Article by Beauchamp et al. <sup>33</sup>	Animals (Chimpanzees)	Research
2016	Article by Jox <sup>34</sup>	Adults (Disorders of consciousness)	Research

recognized in U.S. law in 1983,<sup>19</sup> and in EU law in 2014 (European law recognizes, rather than prescribes assent).<sup>20</sup> This statute is narrowly focused on research with children, but there is a growing body of literature and quasi-regulation in other contexts. Sanford Leikin<sup>21</sup> first proposed that assent might be germane to children’s treatment, and assent has been embraced for this purpose by the American Academy of Paediatrics Committee on Bioethics.<sup>22</sup> Guidelines for research with adults with impaired capacity include discussions of assent,<sup>23</sup> and since 2000 assent has been included as a requirement for research with those lacking decision-making capacity in the Declaration of Helsinki.<sup>24</sup> Assent has been proposed for treatment decisions with incapacitated adults.<sup>25</sup> More recently, assent has been discussed in animal research<sup>26</sup> and research with patients with disorders of consciousness<sup>27</sup> (Table 1).

Despite the widespread invocation of assent, little conceptual work has yet occurred. Indeed, assent may be justified in ways that leave much open to question. For example, in research with children, studies commonly suggest that assent contains elements akin to the need for information, understanding, and voluntariness.<sup>35,36</sup> These elements suggest a *prima facie* link with consent, yet raise the question of whether assent is something distinct or just consent by another name (indeed this substitution has been explicit in some, albeit revisionary, accounts of assent).<sup>37</sup> Assent has now been proposed in very different contexts. We must reflect on how differences in medical treatment and research environments, and a focus on adults or children, affect interpretations of assent (if at all).

### Group Benefits of Assent

While assent is proposed for children in treatment settings,<sup>38</sup> assent is primarily discussed in the context of research. Much of the literature sees refusing assent as a protective mechanism by which children can object to participation in research.<sup>39</sup> Children may also be motivated to take part in research to help other children,<sup>40,41</sup> or later come to appreciate their participation in research as they mature.<sup>42</sup> Potentially, by allowing children’s wishes to be involved in research to be heard, assent may also be viewed as a way to meet this presumed preference of children to participate in non-beneficial research. It may be countered that flaws in children’s understanding render assent of insufficient moral weight to agree to participate in non-beneficial<sup>43</sup> or higher-than-minimal risk trials.<sup>44</sup> Such arguments are not universally accepted. Anna Westra, Jan Wit, Rám Sukhai, and Inez de Beaufort propose accepting assent in order to facilitate research in children where studies are of exceptional value to children’s health at large.<sup>45</sup> They do so not because they believe assent is a sufficient standard of children’s understanding but because assent will facilitate research that will benefit children as a group. Perhaps perversely, such a view apparently conceives assent as a way to reduce the protection of individual children. Indeed, it chimes with critical views that assent is part of a capture of the child research agenda by commercial concerns of the pharmaceutical industry.<sup>46,47</sup>

Assent has gained prominence at a time when the impact on children of the historical lack of research on children’s medicines is a rising concern.<sup>48,49,50</sup> Governments have addressed these concerns by

passing laws to incentivize research in children. Incentives to reward drug companies that conduct research in children include valuable extensions to patents. Yet critics note that pharmaceutical studies in children have therefore disproportionately focused on medicines for diseases that are nearing the end of their patent periods, which are rare in children, but common in adults.<sup>51</sup> Critics argue that (inasmuch as they experience duress for no benefit) this concession has harmed children as a group. In such a situation assent may be viewed in two ways. Refusal of assent may offer additional protection to children against their exploitation, or, by reducing the barrier of need for consent, assent may represent a concession to drug companies to reduce the difficulties in conducting pediatric trials. While the former position sees assent as protective of the individual child, the latter position can still be justified with reference to group benefits. Thus by taking an explicitly collectivist motivation that focuses on accounts of what is good for children at large, assent may assume a quite different character to a more empowerment-led standard. Indeed, since non-therapeutic research itself is clearly aligned to collective benefits, it is unsurprising that a collectivist case for assent in children's research can be made out.

Assent in children's clinical treatment is much less discussed than research, and the putative benefits it offers in this context much less clearly fit the collectivist mold. For example, assent has been argued to protect children's rights<sup>52</sup> and/or reflect the intrinsic good of respecting children as persons.<sup>53</sup> These are concepts that ultimately embrace the broader extension to children of the group benefits adults enjoy (where the prevailing conception of benefit accepts the priority of the good of having a refusal respected over any physical harm arising from refusal). Yet they more clearly confer putative benefit to the child as an individual. This is especially true of the rights justification, given the putative function of rights in protecting the individual from being harmed for the wider good. The small literature focused on assent in the treatment of dementia is silent on the concept of group benefits, but the link between research and collective benefit is, somewhat tenuously—made in the case of dementia research.<sup>54</sup> For example, some contend that research participation allows people with dementia to act altruistically or militates against negative stereotypes of incapacity.<sup>55</sup> These benefits might comfortably be construed as either collective or individual, but tend to be framed as the latter. Given the affinity of non-therapeutic research to a group benefit justification, the rather muted reference to group benefits is interesting. Perhaps it suggests that respect for adults as persons is more firmly entrenched in the bioethical discourse around dementia than similar discourse around children.

### Autonomy and Consent

Assent is sometimes argued to respect the nascent autonomy of pediatric populations,<sup>56</sup> although this argument is regularly criticized.<sup>57,58</sup> Nevertheless, since seeking consent is commonly held to be the gateway to autonomy,<sup>59</sup> there is a tellingly close resemblance (in form if not in function) between assent and consent in children's treatment and research. For example, it is not uncommon for children to be encouraged to sign an "assent form" in a manner that mimics the procedures of seeking consent.<sup>60,61,62</sup>

The tripartite model of informed consent holds that valid consent entails a patient: (1) being provided with the information they need to decide; (2) understanding that information; and (3) making a voluntary decision. These elements are all present in the literature on children's participation in research, and numerous authors model assent on consent.<sup>63,64,65</sup> Children's developmental level varies. Capacity is not simply a corollary of age<sup>66</sup> and some emphasize that the way the information, understanding, and voluntariness manifest can vary from one child to the next.<sup>67</sup> While this lends a certain ambiguity to the presence or absence of assent, many reject the notion that assent is simple affirmation without understanding.<sup>68,69</sup> Moreover, dissent in research is often held to warrant an outright veto.<sup>70</sup> Whatever we decide the exact parameters of dissent are (and I have already noted it shall not be discussed here), the power of dissent suggests that, in children's research, while informedness and understanding may wax and wane from child to child, the requirement for voluntariness is a unifying feature of assent. In contrast, an absolute position on voluntariness and dissent is absent from discussions of children's treatment. The same author on occasion will state expressions of dissent should be determinative while accepting that dissent to treatment might be overridden if it carries a risk of harm.<sup>71</sup> One small empirical

study suggested practitioners' motivation for gaining assent to treatment may be to gain the cooperation of the child and avoid litigation.<sup>72</sup> One may speculate that such a focus may further weaken attention to providing information and securing understanding. Thus, the force of voluntariness in assent may be weakened by attention to preventing harm and, in some cases, shifted further to preventing harm to the practitioner, perhaps at the cost of other consent-like elements.

Those who argue for assent in dementia treatment do not generally attempt to differentiate it from assent in dementia research contexts.<sup>73,74</sup> In this small literature perhaps more than any other, assent lacks conceptual clarity or rigor. Sometimes assent in dementia research is implied to rest on similar grounds to consent<sup>75</sup>; in others assent and consent are not clearly differentiated from one another.<sup>76</sup> In common with children's assent, the form of consent and assent can be similar, with some authors suggesting that the person with dementia should formally sign assent documentation.<sup>77</sup> Partial understanding<sup>78</sup> and lack of objection<sup>79</sup> have corollaries with the "understanding" and "voluntary" elements of consent. While being distinctive ideas, they are suggestive of a common inspiration. Nevertheless, the broad thrust of the literature is suggestive of autonomy as a broader concept. Echoing Gerald Dworkin's influential definition of autonomy as authenticity plus independence,<sup>80</sup> emphasis has been placed on establishing that the assent or dissent of people with dementia expresses an "authentic" choice.<sup>81</sup> Authenticity may be established in two ways: through attention to past values and preferences<sup>82</sup> and through ongoing social engagement<sup>83</sup> between researcher and participant. Engagement teaches the researcher how persons with dementia behaves when their level of well-being is high, and thus indicates their level of comfort which may otherwise not be self-evident.<sup>84</sup> Jan Dewing urges caution when giving attention to past values and preferences because these may devalue the status of the person with dementia in the present.<sup>85</sup>

Despite the centrality of authenticity, it can be difficult to determine in dementia. One study noted that the conversations that people with dementia had with clinicians were skewed toward statements of agreement and approval.<sup>86</sup> People with dementia may be aware of their cognitive impairment and engage in face-saving behaviors that hide their lack of understanding.<sup>87</sup> Family members can have difficulty interpreting the wishes of close relatives with dementia,<sup>88</sup> while professional caregivers may ignore obvious misunderstandings to save the person with dementia embarrassment.<sup>89</sup> Gauging authenticity may therefore be challenging in practice. Notwithstanding Dewing's reservations about devaluing the present person, if there are no overt objections from a person with dementia, it may be impossible to avoid an emphasis on past wishes. Under these circumstances attempts to impute the person with dementia's competent response call to mind some aspects of substituted decision-making, which has been conceived to mean a decision based upon past wishes, presumed current wishes, and best interests.<sup>90</sup> Substituted decision-making has a somewhat contested relationship with autonomy,<sup>91</sup> a topic I will return to in due course.

## Education

Assent in children's research and treatment is argued to have a developmental, or educational, component.<sup>92,93</sup> Leikin<sup>94</sup> argues that encouraging children to assent to treatment develops the future adults' ability to give adequate consent. Less eruditely, one study reported that clinicians view assent to treatment as an obligation to "educate" children about the procedure they would undergo.<sup>95</sup> The same group of clinicians saw assent as a way to gain children's cooperation. Information tailored toward cooperation may differ from information given for its own sake. This differs from the longer-term goals cited in discussions of assent to research. Therein it has been argued that assent teaches children that choices should be respected.<sup>96</sup> Potentially in variance to this, Amanda Sibley, Andrew Pollard, Raymond Fitzpatrick, and Mark Sheehan<sup>97</sup> distinguish this perceived educational property of assent from developing a child's autonomy. Their argument for this is that what is best for a child overall may be stripped away from the child's right to be taught to make optimal decisions. Clearly, if teaching children to make decisions is a good in itself, it need not improve the child's welfare to be morally valid. Nevertheless, even divorced from the child's overall welfare, education implies a developmental

(or perhaps a teleological) goal. Thus education may be about both developing future reasoning, current understanding, or engendering a particular attitude.

It is important to reflect on a more general message the emphasis on what education says about assent. Such goals allow a new perspective on the earlier question of assent and consent, since developmental goals clearly reflect the widespread view that children are “becomings.” Under this view, childhood is a stage where children prepare for adulthood, and this preparation entails a separation between the adult world and the world of children.<sup>98</sup> Assent for children thus could be seen as separated from consent, not because it has separate processes or purposes, but because assent is the way we demonstrate the difference between child and adult interactions with the adult world. Indeed, such an analysis is supported by the absence of an educational justification for assent in people with dementia.

Conceiving assent as a separate, child-centered standard may be viewed positively, as it allows children to assert their views as children, without a need to conform to adult norms or standards. However, this overlooks the fact that assent is itself devised from an adult perspective. Such a perspective stems from an adult view of what children are, how they think, and what they are capable of. If assent requires lower standards of understanding, different types of information, or has specific developmental aims, this firmly casts assent as a vehicle of adult expectations rather than children’s capabilities. Considering children’s participation in research, Rachel Balen, Eric Blyth, Helen Calabretto, Claire Fraser, Christine Horrocks, and Martin Manby note that a real danger is that adult expectations of children’s thinking and understanding may be mistaken.<sup>99</sup> Seeking assent may hardwire our expectations that children will warrant education, since they will have less experience, and thus make poorer decisions, than adults. Such expectations may not represent a universal truth.

### Promoting Paternalistic Welfare and Preventing Harm

The conception of children’s assent in the 1977 National Commission report<sup>100</sup> indicates assent initially had an explicitly paternalistic welfare function. Contemporary comment<sup>101</sup> indicates that the committee was impressed by the argument that assent should be part of a protective function that ensured children’s best interests were not being compromised by their involvement in research. Far from a child’s welfare being synonymous with their parents’ views, the language of the report speaks of seeking parental “permission,” rather than consent, suggesting that parents were not to be seen as exercising proxy autonomy. Rather, assent was to involve researchers and parents jointly determining a child’s welfare, on the basis that each had an independent motivation to both protect (as well as empower) the child. Some recent discussions of assent remain concerned that differences in the views of the parent and the child may lead to the child’s disempowerment.<sup>102</sup> If parents and the researcher/clinician share responsibility for interpreting assent, this implies a limitation of both parental and clinical authority, and offers both a right of veto. A parent and professional veto seems to confirm that sharing authority is focused on the paternalistic promotion of welfare rather than a child’s empowerment. A child cannot veto the veto: offering a dissent-based veto to a child cannot empower a child to decide her or his own welfare. Indeed, if a child’s dissent is overruled, her or his unequal standing in the decision-making process is further compounded.

Perhaps this is why paternalistic welfare promotion is rarely linked to assent outside these early discussions (albeit paternalism per se, especially as exercised by a parent in a pediatric context, is often viewed as appropriate in many cases) and respecting children’s dissent to prevent harm is much more commonly argued. As noted above, many authors argue that dissent should constitute an unambiguous veto, at least in a research context.<sup>103,104</sup> The scope of dissent in treatment decisions is more fluid. It is plausible to argue that welfare benefits flow from having control over a decision.<sup>105</sup> If dissent may be overridden, it is less clear whether benefits flow from having a say but partial or no control over a decision. It has been suggested that the pretense of consultation in a decision may be more detrimental than no consultation at all.<sup>106</sup> Indeed, the insidious effects of learned helplessness have been well documented in numerous contexts.<sup>107</sup> While protections appear to flow from respecting dissent, respecting dissent incompletely has the potential to cause significant harms.

Emphasis on prevention of harm using dissent is repeated in the dementia literature, and here there is less equivocation about the finality of dissent. While there is some suggestion in treatment contexts that clinicians have a paternalistic welfare role that expressly limits the decision-making authority of families over relatives with dementia,<sup>108-109</sup> in general, it is the case that dissent is seen to be a more powerful guide to withdrawal from research or treatment than assent is a guide to participation.<sup>110-111</sup>

### Critiquing the Possible Justifications for Assent

The discussion above shows a number of justifications for assent. Justifications based on what could broadly be construed as “autonomy” were found in every context (all or most elements of consent were suggested as properties of assent). Avoiding harm by respecting dissent, was found in all but dementia treatment contexts. A paternalistic welfare basis where assent was subject to the shared interpretation of clinicians/researchers was found in research with children and in treatment contexts with children and people with dementia. Justification of assent as educative was found in treatment and research contexts with children but not with people with dementia. Finally, group benefits are used to justify assent only in research with children (Table 2).

These findings underline questions about the ability of assent to offer a consistent approach. This is true both within specific groups when the weight given to particular justifications may cause the approach to differ and when it is used across disparate groups and circumstances. An example of the first instance is assent in children’s research. An emphasis placed on assent as autonomy places a high bar on the understanding and agency of the child who is approached in every case, while an emphasis on assent as educational instead emphasizes the essentially contingent nature of their assent, given its only basis is to teach when we can be certain the child’s decision does not matter. A greater weight given to dissent may grant the power of veto to children even if they do not understand what they are vetoing. An emphasis on paternalistic welfare may allow a researcher to veto the child’s research participation even if the child and their parents strongly disagree. Depending on the exact nature of the group benefit sought and their cost to the individual, an emphasis on group benefit potentiates considerable individual harm even if a child’s understanding is poor or they have little agency. This problem is not an absolute one—any or all of these choices may potentially be used in morally justifiable ways. Yet they may just as easily be used in ways that are not justifiable, for instance, to increase the convenience of a third party such as a family member or a practitioner (for example, by ignoring a child’s dissent because a parent insists on treatment) or to advance an interest of a researcher (for example, by accepting an assent to research where uptake is low and time is short, even though it is clear that the participant has no understanding of what she or he assents to). Such abuses may be unavoidable if they arise from misconduct. However, the threads of justification for assent are sufficiently diverse that there is also scope for a variety of good-faith understandings. While allowing enough scope for discretionary response to unique circumstances is undoubtedly a good thing, without an underlying and coherent justification for assent the range and scope of responses may be too wide. Assent may be an instance where anything goes: Indeed the rich

**Table 2.** Recurring Justifications for Assent

Context	Autonomy	Education	Harm	Welfare	Group benefit
Children research	Consent	Education	Dissent	Limits on family	Benefit children at large
Children treatment	Information and understanding	Education	Dissent	Limits on family	
Dementia research	Consent / Authenticity / Past values		Dissent		
Dementia treatment	Consent / Authenticity / Past values			Limits on family	

tapestry of interpretations suggests that assent may easily articulate a spectrum of (potentially) justifiable paternalistic and unjustifiable coercive ends, since no such end will encounter a firm conceptual obstacle.

In the face of these problems, it is tempting to cut the Gordian knot and return assent to its natural limits. In the next section, I will explore the suggestion that there is a natural context and motivation for assent. In at least one of these contexts, I suggest we might at last make more of what is an increasingly attractive idea—the extension of the benefits of autonomy to those who hitherto have been denied them.

### Contextually Appropriate Homes for Assent

In any reading of the assent literature, it is impossible to ignore the relationship between assent and legal standards of consent for children. Assent is held by many authors as a moral device to enhance legal provisions,<sup>112,113,114</sup> yet the legal rights of children to consent can and do vary from one jurisdiction to another. Priscilla Alderson<sup>115</sup> has identified assent with U.S. culture. Her concern is that a wholesale importation of assent from the United States to other jurisdictions, as has taken place in UK research, may distort their national approaches toward the rights of children.<sup>116,117</sup> Alderson's attention to context is instructive: Given the apparent interpretability of assent, a context-sensitive approach to background conditions may be justified.

This explicit differentiation of the ethical nature of assent from the legal context suggests that the concept of assent can be implicitly linked to a liberalization of the U.S. legal approach to children's consent. U.S. law confers the right to consent on "mature minors"—children above a threshold age (which varies between states) who are alienated from their parents. However, while often some or all minors can independently consent to a narrow range of care and treatment,<sup>118</sup> where parents are not alienated from their children the parents, rather than their child, retain a right to consent to the bulk of treatment. This position is rather different from the English common law position.<sup>119,120</sup> Alderson argues this grants children of all ages significant rights to consent whatever their relationship with their parents, provided a child is judged competent to make decisions. English law in this area is, however, complex and somewhat incoherent,<sup>121</sup> containing as it does a peculiar situation where children can consent but not refuse, treatment. UK practitioners may already be unclear about the legal position in many situations involving children's consent,<sup>122</sup> and the range of justifications for assent may sow further confusion. There appears similar potential for complications on the European mainland.<sup>123</sup>

While bespoke tailoring of assent for particular U.S. contexts may create problems for its cogency in other areas, it does suggest a solution to the possible muddle of concepts and situations we currently find attached to assent. Assent for children seems in the U.S. context to be a candidate for doing the work we would otherwise expect of the United Nations Convention on the Rights of the Child (UNCRC)<sup>124</sup> performs in other contexts. The UNCRC seeks to balance the best interests of the child (Article 3) and a right to participation (Article 12). Moreover, in discussing children's welfare as "a primary" concern, the language of the convention itself was intended to allow a balance between the rights of parents and siblings (and wider society) and the rights of the child.<sup>125,126</sup> The UNCRC has not been ratified in the United States, and much of the critique inimical to children's rights emanates from U.S. scholars.<sup>127,128,129,130</sup> The strands of autonomy, harm, paternalistic welfare, and group benefit found within many of discussions of assent seem to make similar attempts to balance the rights of parents, the rights and welfare of individual children, and the rights and welfare of children at large. Perceiving assent in this way depends on defining assent in particular ways, which may not be acceptable to all commentators. Most glaringly, it relies on a rejection of Sibley, Pollard, Fitzpatrick, and Sheehan's contention that the aims of assent can be stripped away from the child's best interests.<sup>131</sup> Yet, potentially, this claim is influenced by local culture, emanating as it does from an English institution where the different legal standing of children will affect the types of justification that are offered for assent.

If this analysis is correct, then a cogent way to view children's assent might be as a specific doctrine that answers some dilemmas about children's rights in the United States. Seeking assent may therefore be justified in treatment and research decisions in the United States, while being an imperfect fit for the problems of treating and doing research with children elsewhere. In other jurisdictions, children will



suffer their own distinctive constellations of inattention, abuse, and oppression that may be better addressed in other ways. This draws into question the need for assent in contexts where the UNCRC has been more influential on the law. This is certainly the case in English Law where the Children Act 1989 gives effect to many of the provisions of the UNCRC. Although the situation is not perfect,<sup>132</sup> the UNCRC is increasingly affecting policy-making throughout the UK.<sup>133</sup>

This analysis of assent in children sees assent as a parochial concept and raises questions about whether assent is fit for other populations. This seems a contentious end for assent. Many find assent an intuitively attractive way to advance liberalism in healthcare, perhaps because it seems to offer the prospect of extending the autonomy of individuals in marginalized and overlooked populations. Although the context of dementia is different, it may ultimately guide us to a place for assent more in keeping with this liberating agenda. There is a developing international approach to the problems of the binary approach to incapacity. The emphasis on judging the authenticity of the assent of a person with dementia raises questions about the place and validity of a substituted decision-making approach. Such approaches have been defended, largely due to the relative unacceptability of alternatives.<sup>134,135</sup> Despite such pragmatic arguments, substituted decision-making faces a mounting critique, having been roundly condemned by the U.N. Committee on the Rights of Persons with Disabilities (CRPD) because of their potential to thwart the rights and actual preferences of people with disabilities.<sup>136</sup> The tendencies to disvalue the current experience of a disabled person over their past preference, to perceive we know a person better than we actually may,<sup>137</sup> or to over-extrapolate from distant events, have been argued to make substituted decisions speculative and their truth-value theoretically problematic.<sup>138</sup> The CRPD claims the better alternative is supported decision-making, where a person who has difficulties in understanding, making, or communicating a decision is given adequate help and resources to overcome these difficulties. A commitment to supported decision-making raises a host of questions, including how it should apply to those people whose level of decision-making ability is extremely low. Supported decision-making approaches are under-researched and far from being fully operationalized.<sup>139</sup> Yet it is impossible to ignore the potential for assent to complement such an approach in treatment and research decisions. Perhaps then, attempts to spread the solicitation of assent in dementia research and practice should find common causes with the quest to develop robust solutions to supported decision-making. Indeed, a more radical claim, prompted by the connection assent highlights between children and incapacitated adults, is that both children and adults should benefit equally from the move away from blanket judgments of capacity and incapacity to receive similar attention to their liberty and welfare. This could build on the potential of supported decision-making to enhance autonomy, offering support based on need, irrespective of whether a person is a child, has dementia, or is an otherwise competent adult struggling with a particular decision.

Assent should be regarded as part of a global movement that, however imperfectly, has taken faltering steps toward these possibilities; indeed, recent attempts to apply assent to the treatment of animals are likely to strengthen this analysis. That these steps have resulted in an unfinished and potentially inconsistent concept highlights the urgent need to develop coherent theoretical foundations to meet the shared dilemmas we encounter when we dissolve the walls between capacity and incapacity. Such an accomplishment may allow assent to fulfill its intuitive promise.

## Conclusion

As a mechanism to include children in research, assent has entered law, research, and treatment contexts. Yet it remains conceptually hollow. My analysis suggests five justifications of assent that may struggle to promote a coherent and consistent approach in all instances assent is invoked. Taking my analysis further, I have argued assent may need to attend to the background conditions in specific contexts in which it is used, and discussed two contexts where I believe assent might be usefully deployed. Of these, I suggest the most worthy project is to tie assent to the growing international movement attempting to address the lacunae that are created by binary approaches to decision-making. The intuitive appeal of assent to many lies in its apparent potential to address this area. Since assent currently lacks firm

theoretical foundations to underpin a stable and consistent usage in practice, it is to these theoretical foundations of assent that future research should be addressed.

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## Notes

1. De Lourdes Levy M, Larcher V, Kurz R, Ethics working group of the confederation of European specialists in Paediatrics. Informed consent/assent in children. Statement of the ethics working group of the confederation of European specialists in paediatrics (CESP). *European Journal of Pediatrics* 2003;**162**(9):629–33.
2. Tait AR, Geisser ME. Development of a consensus operational definition of child assent for research. *BMC Medical Ethics* 2017;**18**(1):41.
3. Health Research Authority. *Standard Operating Procedures for Research Ethics Committees Version 7.2*. London: Department of Health; 2017.
4. UK Government. *The Medicines for Human Use (Clinical Trials) Regulations SI 2004/1031*. London/England: HMSO; 2004.
5. European Parliament and Council of the European Union. *Regulation (EU) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on Clinical Trials on Medicinal Products for Human Use, and Repealing Directive 2001/20/EC*. Brussels/Belgium: European Union; 2014.
6. Unguru Y. Making sense of adolescent decision making: Challenge and reality. *Adolescent Medicine: State of the Art Reviews* 2011;**22**(2):195–206.
7. Gershoff ET, Bitensky SH. The case against corporal punishment of children: Converging evidence from social science research and international human rights law and implications for U.S. public policy. *Psychology, Public Policy, and Law* 2007;**13**(4):231–72.
8. Alderson P. Children's consent and 'assent' to healthcare research. In: Freeman M, ed. *Law and Childhood Studies: Current Legal Issues*. Vol. 14. Oxford: Oxford University Press; 2012:174–89.
9. Bos W, Westra A, de Beaufort I, van de Vathorst S. To stop or not to stop: Dissent and undue burden as reasons to stop participation in paediatric research. *Journal of Medical Ethics* 2017;**43**(8):519–23.
10. Bielby P. The conflation of competence and capacity in english medical law: A philosophical critique. *Medicine, Health Care and Philosophy* 2005;**8**(3):357–69.
11. Ruhe KM, Wangmo T, Badarau DO, Elger BS, Niggli F. Decision-making capacity of children and adolescents—Suggestions for advancing the concept's implementation in pediatric healthcare. *European Journal of Pediatrics* 2015;**174**(6):775–82.
12. Kissin M, Towers K. Standards for determination of competence. *Journal of the American Academy of Psychiatry and the Law* 2007;**35**(3):386–8.
13. Berg JW, Appelbaum PS, Grisso T. Constructing competence: Formulating standards of legal competence to make medical decisions. *Rutgers Law Review* 1996;**48**(2):345–96.
14. Ashtekar CS, Hande A, Stallard E, Tuthill D. How much do junior staff know about common legal situations in paediatrics? *Child: Care, Health and Development* 2007;**33**(5):631–4.
15. Schofield C. Mental capacity act 2005—What do doctors know? *Medicine, Science and the Law* 2008;**48**(2):113–6.
16. Cave E. Goodbye gillick? Identifying and resolving problems with the concept of child competence. *Legal Studies* 2014;**34**(1):103–22.
17. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *Report and Recommendations: Research Involving Children*; 1978.
18. Waltz J, Scheuneman T. Informed consent to therapy. *Northwestern University Law Review* 1970;**64**(5):628–50.
19. US Government, United States Code of Federal Regulations 45 CFR 46, Subpart D; 1983.

20. European Union, Regulation (EU) 536/2014; 2014.
21. Leikin SL. Minors' assent or dissent to medical treatment. *Journal of Pediatrics* 1983;**102**(2):169–76.
22. American Academy of Paediatrics Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995;**95**(2):314–7.
23. Keyserlingk EW, Glass K, Kogan S, Gauthier S. Proposed guidelines for the participation of persons with dementia as research subjects. *Perspectives in Biology and Medicine* 1995;**38**(2):317–62.
24. World Medical Association. Declaration of Helsinki – Ethical Principles for Human Research Involving Human Subjects. *Amended by the 64th WMA General Assembly*. Ferney-Voltaire France: World Medical Association; 2013.
25. Fisk JD, Beattie BL, Donnelly M. Ethical considerations for decision making for treatment and research participation. *Alzheimer's and Dementia* 2007;**3**(4):411–7.
26. Beauchamp TL, Ferdowsian HR, Gluck JP. Where are we in the justification of research involving chimpanzees? *Kennedy Institute of Ethics Journal* 2012;**22**(3):211–42.
27. Jox RJ. Disorders of consciousness and informed consent. In: Farisco ME, Evers K, eds. *Neurotechnology and Direct Brain Communication: New Insights and Responsibilities Concerning Speechless But Communicative Subjects*. London: Routledge; 2016:133–42.
28. See [note 17](#), National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978.
29. See [note 21](#), Leikin 1983, at 169–76.
30. See [note 23](#), Keyserling et al. 1995, at 317–62.
31. World Medical Association. Declaration of Helsinki - Ethical Principles for Human Research Involving Human Subjects. *Amended by the 52nd WMA General Assembly*. Ferney-Voltaire, France: World Medical Association; 2000.
32. Molinari V, McCollough LB, Workman R, Coverdale J. Geriatric assent. *Journal of Clinical Ethics* 2004;**15**(3):261–8.
33. See [note 26](#), Beauchamp 2012, at 211–42.
34. See [note 27](#), Jox 2016, at 133–42.
35. See [note 8](#), Alderson 2012, at 174–89.
36. Waligora M, Rozynska J, Piasecki J. Child's objection to non-beneficial research: Capacity and distress based models. *Medicine, Health Care and Philosophy* 2016;**19**(1):65–70.
37. Wendler D, Shah S. Should children decide whether they are enrolled in nonbeneficial research? *American Journal of Bioethics* 2003;**3**(4):1–7.
38. Koshy AJ, Sisti DA. Assent as an ethical imperative in the treatment of ADHD. *Journal of Medical Ethics* 2015;**41**(12):977–81.
39. Modi N, Vohra J, Preston J, Elliott C, Van't Hoff W, Coad J, et al. Guidance on clinical research involving infants, children and young people: An update for researchers and research ethics committees. *Archives of Disease in Childhood* 2014;**99**(10):887–91.
40. Poston RD. Assent described: Exploring perspectives from the inside. *Journal of Pediatric Nursing* 2016;**31**(6):e353–65.
41. Wolthers OD. A questionnaire on factors influencing children's assent and dissent to non-therapeutic research. *Journal of Medical Ethics* 2006;**32**(5):292–7.
42. Redmon RB. How children can be respected as 'ends' yet still be used as subjects in non-therapeutic research. *Journal of Medical Ethics* 1986;**12**(2):77–82.
43. See [note 37](#), Wendler, Shah 2003, at 1–7.
44. Shah SK. When to start paediatric testing of the adult HIV cure research agenda? *Journal of Medical Ethics* 2017;**43**(2):82–6.
45. Westra AE, Wit JM, Sukhai RN, de Beaufort ID. Regulating “higher risk, no direct benefit” studies in minors. *American Journal of Bioethics* 2011;**11**(6):29–31.
46. See [note 8](#), Alderson 2012, at 174–89.
47. Sharav VH. Children in clinical research: A conflict of moral values. *American Journal of Bioethics* 2003;**3**(1):12–59.
48. Saint Raymond A, Brasseur D. Development of medicines for children in Europe: Ethical implications. *Paediatric Respiratory Reviews* 2005;**6**(1):45–51.

49. Snyder J, Miller CL, Gray G. Relative versus absolute standards for everyday risk in adolescent HIV prevention trials: Expanding the debate. *American Journal of Bioethics* 2011;**11**(6):5–13.
50. Nuffield Council on Bioethics. *Children and Clinical Research: Ethical Issues*. London: Nuffield Council on Bioethics; 2015.
51. Permanand G, Mossialos E, McKee M. The EU's new paediatric medicines legislation: Serving children's needs? *Archives of Disease in Childhood* 2007;**92**(9):808–11.
52. See note 6, Unguru 2011, at 195–206.
53. See note 38, Koshy, Sisti 2015, at 977–81.
54. Black BS, Rabins PV, Sugarman J, Karlawish JH. Seeking assent and respecting dissent in dementia research. *American Journal of Geriatric Psychiatry* 2010;**18**(1):77–85.
55. Slaughter S, Cole D, Jennings E, Reimer MA. Consent and assent to participate in research from people with dementia. *Nursing Ethics* 2007;**14**(1):27–40.
56. Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics* 2016;**138**(2):e20161485.
57. Diekema DS. Taking children seriously: What's so important about assent? *American Journal of Bioethics* 2003;**3**(4):25–6.
58. Sibley A, Pollard AJ, Fitzpatrick R, Sheehan M. Developing a new justification for assent. *BMC Medical Ethics* 2016;**17**:2.
59. Beauchamp TL. Autonomy and consent. In: Miller F, Wertheimer A, eds. *The Ethics of Consent: Theory and Practice*. Abingdon: Oxford University Press; 2009: 55–75.
60. Ungar D, Joffe S, Kodish E. Children are not small adults: Documentation of assent for research involving children. *Journal of Pediatrics* 2006;**149**(1 Suppl):S31–3.
61. Ford K, Sankey J, Crisp J. Development of children's assent documents using a child-centred approach. *Journal of Child Health Care* 2007;**11**(1):19–28.
62. Dockett S, Perry B. Researching with young children: Seeking assent. *Child Indicators Research* 2010;**4**(2):231–47.
63. Rossi WC, Reynolds W, Nelson RM. Child assent and parental permission in pediatric research. *Theoretical Medicine and Bioethics* 2003;**24**(2):131–48.
64. Giesbertz NA, Bredenoord AL, van Delden JJ. Clarifying assent in pediatric research. *European Journal of Human Genetics* 2014;**22**(2):266–9.
65. Westra AE, de Beaufort I. Improving the Helsinki declaration's guidance on research in incompetent subjects. *Journal of Medical Ethics* 2015;**41**(3):278–80.
66. Alderson P. Children's consent and the zone of parental discretion. *Clinical Ethics* 2017;**12**(2):55–62.
67. Wendler DS. Assent in paediatric research: Theoretical and practical considerations. *Journal of Medical Ethics* 2006;**32**(4):229–34.
68. See note 6, Unguru 2011, at 195–206.
69. Joffe S. Rethink “affirmative agreement,” but abandon “assent”. *American Journal of Bioethics* 2003;**3**(4):9–11.
70. See note 36, Waligora et al. 2016, at 65–70.
71. Pate MF. Assent and dissent in pediatric progressive and critical care. *AACN Advanced Critical Care* 2013;**24**(4):356–9.
72. Lee KJ, Havens PL, Sato TT, Hoffman GM, Leuthner SR. Assent for treatment: Clinician knowledge, attitudes, and practice. *Pediatrics* 2006;**118**(2):723–30.
73. See note 25, Fisk et al. 2007, at 411–7.
74. Molinari V, McCullough LB, Coverdale JH, Workman R. Principles and practice of geriatric assent. *Aging and Mental Health* 2006;**10**(1):48–54.
75. Beuscher L, Grando VT. Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing* 2009;**2**(1):6–11.
76. See note 25, Fisk et al. 2007, at 411–7.
77. Cridland EK, Phillipson L, Brennan-Horley C, Swaffer K. Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research* 2016;**26**(13):1774–86.

78. See note 23, Keyserling et al. 1995:317–62.
79. Dewing J. Participatory research: A method for process consent with persons who have dementia. *Dementia* 2007;**6**(1):11–25.
80. Dworkin G. Autonomy and behavior control. *The Hastings Center Report* 1976;**6**(1):23–8.
81. See note 54, Black et al. 2010, at 77–85.
82. See note 54, Black et al. 2010, at 77–85.
83. See note 55, Slaughter et al. 2007, at 27–40.
84. See note 79, Dewing 2007, at 11–25.
85. Dewing J. From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia* 2002;**1**(2):157–71.
86. Sugarman J, Roter D, Cain C, Wallace R, Schmechel D, Welsh-Bohmer KA. Proxies and consent discussions for dementia research. *Journal of the American Geriatrics Society* 2007;**55**(4):556–61.
87. Dooley J, Bailey C, McCabe R. Communication in healthcare interactions in dementia: A systematic review of observational studies. *International Psychogeriatrics* 2015;**27**(8):1277–300.
88. Fetherstonhaugh D, McAuliffe L, Bauer M, Shanley C. Decision-making on behalf of people living with dementia: How do surrogates decision-makers decide? *Journal of Medical Ethics* 2017;**43**(1):35–40.
89. Lindholm C, Wray A. Proverbs and formulaic sequences in the language of elderly people with dementia. *Dementia* 2011;**10**(4):603–23.
90. Scholten M, Gather J. Adverse consequences of article 12 of the UN convention on the rights of persons with disabilities for persons with mental disabilities and an alternative way forward. *Journal of Medical Ethics* 2018;**44**(4):226–33.
91. Phillips J, Wendler D. Clarifying substituted judgement: The endorsed life approach. *Journal of Medical Ethics* 2015;**41**(9):723–30.
92. See note 64, Giesbertz et al. 2014, at 266–9.
93. See note 67, Wendler 2006, at 229–34.
94. See note 21, Leikin 1983, at 169–76.
95. See note 72, Lee et al. 2006, at 723–30.
96. See note 57, Diekema 2003, at 25–6.
97. See note 58, Sibley et al. 2016, at 2.
98. Cassidy C. Children’s status, children’s rights and dealing with children. *International Journal of Children’s Rights* 2012;**20**(1):57–71.
99. Balen R, Blyth E, Calabretto H, Fraser C, Horrocks C, Manby M. Involving children in health and social research. *Childhood* 2016;**13**(1):29–48.
100. See note 17, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978.
101. McCartney JJ. Research on Children – National Commission Says Yes, If. *Hastings Center Report* 1978;**8**(5):26–31.
102. Madden L, Shilling V, Woolfall K, Sowden E, Smyth RL, Williamson PR, et al. Questioning assent: How are children’s views included as families make decisions about clinical trials? *Child: Care, Health and Development* 2016;**42**(6):900–8.
103. See note 39, Modi et al. 2014, at 887–91.
104. See note 62, Dockett, Perry 2010, at 231–47.
105. See note 38, Koshy, Sisti 2015, at 977–81.
106. Alderson P, Montgomery J. *Health Care Choices: Making Decisions with Children*. London: Institute for Public Policy Research; 1996.
107. Filippello P, Sorrenti L, Buzzai C, Costa S. Perceived parental psychological control and learned helplessness: The role of school self-efficacy. *School Mental Health* 2015;**7**(4):298–310.
108. See note 32, Molinari et al. 2004, at 261–8.
109. Coverdale J, McCullough LB, Molinari V, Workman R. Ethically justified clinical strategies for promoting geriatric assent. *International Journal of Geriatric Psychiatry* 2006;**21**(2):151–7.
110. See note 54, Black et al. 2010, at 77–85.

111. See note 86, Sugarman et al. 2007, at 556–61.
112. See note 6, Unguru 2011, at 195–206.
113. See note 38, Koshy, Sisti 2015, at 977–81.
114. See note 67, Wendler 2006, at 229–34.
115. See note 8, Alderson 2012, at 174–89.
116. See note 8, Alderson 2012, at 174–89.
117. See note 66, Alderson 2017, at 55–62.
118. National District Attorneys Association. *Minor Consent to Treatment Laws, January, 2013*; available at <https://ndaa.org/wp-content/uploads/Minor-Consent-to-Medical-Treatment-2.pdf> (last accessed 30 July 2019).
119. See note 8, Alderson 2012, at 174–89.
120. See note 66, Alderson 2017, at 55–62.
121. See note 16, Cave 2014, at 103–22.
122. See note 14, Ashtekar et al. 2007, at 631–4.
123. See note 11, Ruhe et al. 2015, at 775–82.
124. United Nations, *Convention on the Rights of the Child*. New York: United Nations; 1989; available at <http://www2.ohchr.org/english/law/pdf/crc.pdf> (last accessed 30 July 2019).
125. Alston P. The best interests principle: Towards a reconciliation of culture and human rights. *International Journal of Law, Policy and the Family* 1994;8(1):1–25.
126. Archard D. Children's rights. In: Zalta EN, ed. *The Stanford Encyclopedia of Philosophy* (Winter 2018 Edition) Stanford: Stanford University; available at <https://plato.stanford.edu/archives/win2018/entries/rights-children/> (last accessed 30 July 2019).
127. Engelhardt Jr HT. Beyond the best interests of children: Four views of the family and of foundational disagreements regarding pediatric decision making. *Journal of Medicine and Philosophy* 2010;35(5):499–517.
128. Erickson SA. The wrong of rights: The moral authority of the family. *Journal of Medicine and Philosophy* 2010;35(5):600–16.
129. Salter EK. Resisting the siren call of individualism in pediatric decision-making and the role of relational interests. *Journal of Medicine and Philosophy* 2014;39(1):26–40.
130. Cherry MJ. Re-thinking the role of the family in medical decision-making. *Journal of Medicine and Philosophy* 2015;40(4):451–72.
131. See note 58, Sibley et al. 2016, at 2.
132. See note 98, Cassidy 2012, at 57–71.
133. See note 16, Cave 2014, at 103–22.
134. See note 90, Scholten, Gather 2018, at 226–33.
135. See note 91, Phillips, Wendler 2015, at 723–30.
136. United Nations, Committee on the Rights of Persons with Disabilities. *Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland*. Geneva: United Nations; 2017.
137. Birchley G. '...What god and the angels know of us?' Character, autonomy, and best interests in minimally conscious state. *Medical Law Review* 2018;26(3):392–420.
138. Wrigley A. The problem of counterfactuals in substituted judgement decision-making. *Journal of Applied Philosophy* 2011;28(2):169–87.
139. Gooding P. Navigating the 'flashing amber lights' of the right to legal capacity in the united nations convention on the rights of persons with disabilities: Responding to major concerns. *Human Rights Law Review* 2015;15(1):45–71.