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See table of contents

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Article abstract

Autonomy is a primary guiding healthcare ethics principle in Western liberal societies. Generally speaking, the principle means that we ought to respect individuals' decisions in relation to themselves, even when such decisions are risky from some perspectives. The principle of autonomy may be of particular importance when thinking about marginalized populations whose ability to make autonomous decisions, and to have such decisions respected (by enabling the autonomous decision to occur through positive or negative means), was largely, historically non-existent. One of these populations is people with intellectual and developmental disabilities (IDD). When it comes to a person with IDD making an autonomous risky decision, a clinician may respect their decision because of the typical weight and priority given to the principle of autonomy. However, this paper argues that a person with IDD's autonomous risky decision related to care provision should *only* be respected insofar as the clinician has demonstrated trustworthiness in an effort to obtain trust. In other words, I argue that unless a clinician has demonstrated that they are trustworthy, then a risky autonomous decision related to care provision should *not* be immediately respected when working with a person with IDD. The reason that a risky autonomous decision should *not* be respected unless there is demonstrated trustworthiness is because of how trustworthiness may influence decision-making insofar as trust is gained. If a person with IDD makes a risky decision without finding their provider to be trustworthy, then their decision may be unnecessarily motivated by lack of trust. There are good reasons that a person with IDD may not find their clinicians to be trustworthy, hence the rationale for ensuring the intentional demonstration of trustworthiness before respect for autonomous risky decision-making.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Respect for Autonomous Risky Decisions and People with IDD: Prioritizing Healthcare Provider Trustworthiness

Andria Bianchi[a,b,c]

Résumé
L'autonomie est l'un des principaux principes directeurs de l'éthique des soins de santé dans les sociétés libérales occidentales. D'une manière générale, ce principe signifie que nous devons respecter les décisions des individus par rapport à eux-mêmes, même si ces décisions sont risquées d'un certain point de vue. Le principe d'autonomie peut revêtir une importance particulière lorsque l'on pense aux populations marginalisées dont la capacité à prendre des décisions autonomes et à faire respecter ces décisions (en permettant à la décision autonome de se produire par des moyens positifs ou négatifs) a été largement, historiquement inexistante. L'une de ces populations est constituée par les personnes atteintes de déficiences intellectuelles et de troubles du développement (DITD). Lorsqu'une personne atteinte d'une DITD prend une décision autonome et risquée, un clinicien peut respecter sa décision en raison du poids et de la priorité généralement accordés au principe d'autonomie. Toutefois, cet article soutient que la décision autonome et risquée d'une personne atteinte de DITD concernant la prestation de soins ne devrait être respectée que dans la mesure où le clinicien a démontré qu'il était digne de confiance dans le but d'obtenir la confiance. En d'autres termes, je soutiens qu'à moins qu'un clinicien n'ait démontré qu'il est digne de confiance, une décision autonome risquée liée à la prestation de soins ne devrait pas être immédiatement respectée lorsqu'on travaille avec une personne atteinte de DITD. La raison pour laquelle une décision autonome risquée ne devrait pas être respectée à moins qu'il n'ait été démontré qu'il est digne de confiance est la façon dont la fiabilité peut influencer la prise de décision dans la mesure où la confiance est gagnée. Si une personne atteinte de DITD prend une décision risquée sans avoir trouvé son prestataire digne de confiance, sa décision peut être inutilement motivée par un manque de confiance. Il y a de bonnes raisons pour qu'une personne atteinte de DITD ne trouve pas ses cliniciens dignes de confiance, d'où la nécessité d'assurer la démonstration intentionnelle de la fiabilité avant le respect de la prise de décision autonome et risquée.

Mots-clés
déficience intellectuelle, trouble du développement, confiance, fiabilité, autonomie, risque, éthique

Abstract
Autonomy is a primary guiding healthcare ethics principle in Western liberal societies. Generally speaking, the principle means that we ought to respect individuals' decisions in relation to themselves, even when such decisions are risky from some perspectives. The principle of autonomy may be of particular importance when thinking about marginalized populations whose ability to make autonomous decisions, and to have such decisions respected (by enabling the autonomous decision to occur through positive or negative means), was largely, historically non-existent. One of these populations is people with intellectual and developmental disabilities (IDD). When it comes to a person with IDD making an autonomous risky decision, a clinician may respect their decision because of the typical weight and priority given to the principle of autonomy. However, this paper argues that a person with IDD's autonomous risky decision related to care provision should *only* be respected insofar as the clinician has demonstrated trustworthiness in an effort to obtain trust. In other words, I argue that unless a clinician has demonstrated that they are trustworthy, then a risky autonomous decision related to care provision should *not* be immediately respected when working with a person with IDD. The reason that a risky autonomous decision should *not* be respected unless there is demonstrated trustworthiness is because of how trustworthiness may influence decision-making insofar as trust is gained. If a person with IDD makes a risky decision without finding their provider to be trustworthy, then their decision may be unnecessarily motivated by lack of trust. There are good reasons that a person with IDD may not find their clinicians to be trustworthy, hence the rationale for ensuring the intentional demonstration of trustworthiness before respect for autonomous risky decision-making.

Keywords
intellectual disability, developmental disability, trust, trustworthiness, autonomy, risk, ethics

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INTRODUCTION

As per Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), people with intellectual and developmental disabilities (IDD) have the right to attain the highest standard of health and to access relevant health services without discrimination (1). This UNCPRD Article is important, particularly since people with IDD may have an increased need to access health services and at earlier points in their life due to health discrepancies that exist between them and the general population. It is well known that people with IDD have a decreased life expectancy and increased risk of morbidity when compared to people without IDD (2-5), and although this discrepancy has decreased over the years, it continues to exist (4-9). When a person with IDD gains access to required care, several kinds of ethical dilemmas may arise in relation to care provision (10). An ethical dilemma occurs when a conflict exists amongst two competing ethics principles.

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Four principles frequently cited in the bioethics literature, which encompass what is often referred to as “principlism”, are autonomy, beneficence, non-maleficence, and justice (11). When a conflict or tension arises amongst these principles, then it is typically suggested that one engage in a weighing and balancing act to determine which principle ought to be prioritized (11).

In Western liberal societies, it is often the case that — even after working through a weighing and balancing act — the principle of autonomy is prioritized or, at the very least, not easily de-prioritized in light of another principle or process. The principle of autonomy, as will be described more thoroughly below, generally means that we ought to respect individuals’ decisions in relation to themselves and their self-determination. For the purposes of this article, respecting a person’s autonomous decision means enabling them to act autonomously through positive or negative means. The principle of autonomy is of particular importance when thinking about certain marginalized populations whose ability to make autonomous decisions, and to have such decisions respected, was largely, historically non-existent. One of these populations is people with IDD.

When working with people with IDD, one reason that the principle of autonomy and the related concept of self-determination may be even further prioritized is because of the dignity of risk (12). The dignity of risk offers an argument as to why one should respect a person with IDD’s risky (or, at least, seemingly risky) autonomous decision(s), including risky decisions related to care provision (e.g., refusing a recommended health service) and overall lifestyle. When it comes to a person with IDD making a risky decision in relation to care provision, it may be the case that a healthcare provider (HCP)[1] respects the decision rather immediately because of the typical weight and priority given to respect for autonomy and the dignity of risk.[2] However, this paper argues that a person with IDD’s autonomous risky decision should *only* be respected insofar as the HCP has taken the time to demonstrate trustworthiness.

In other words, I argue that unless a HCP has demonstrated that they are trustworthy, then a risky autonomous decision related to care provision should *not* be immediately respected. The reason as to why a risky autonomous decision should *not* be respected unless there is trustworthiness is because of the influence that trustworthiness may have on decision-making due to an anticipated increase in trust on part of the person receiving care. If a person with IDD makes a risky decision without their HCP being trustworthy, then their risky decision may be unnecessarily motivated by lack of trust (insofar as lack of trust may be influenced by a HCP’s failure to demonstrate trustworthiness).[3] There are good reasons as to why a person with IDD may not find HCPs to be inherently trustworthy hence the rationale for ensuring the intentional demonstration of trustworthiness. It ought to be noted that a HCP’s demonstration of trustworthiness does not necessarily guarantee that their patient/client will trust them. However, insofar as trustworthiness may be an influential factor that is within the control of HCPs, then it ought to be prioritized in anticipation of it influencing trust.

In order to make this argument regarding the need to prioritize the demonstration of trustworthiness before respecting a person with IDD’s autonomous risky decision, I first offer some definitions and general information related to people with IDD and health/healthcare. I then describe the principle of autonomy and the related concept of dignity of risk, before offering a case example wherein a person with IDD makes a risky decision related to care provision. In this scenario, the person’s risky decision is respected because it is considered autonomous (and respect for autonomy is immediately prioritized). This is followed by a competing argument and suggestion that the demonstration of trustworthiness ought to be prioritized in advance of respecting the person with IDD’s risky decision; in this section, Annette Baier’s concept of trust is referenced. Some potential objections to prioritizing trustworthiness in advance of respecting an autonomous risky decision are then explored, as well as potential responses. Finally, the paper concludes by emphasizing that HCPs ought to pause and prioritize the demonstration of trustworthiness in advance of respecting a person with IDD’s autonomous risky decision related to care. Although some basic suggestions about how to demonstrate trustworthiness are mentioned, more work needs to be done in relation to this topic with a focus on people with IDD.

SETTING THE STAGE: IDD AND HEALTHCARE

The purpose of this section is to ensure there exists conceptional and definitional clarity on IDD. Additionally, this section highlights some of the most frequently occurring health conditions and discrepancies for this population, which may result in hospital admissions.

As per the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), a diagnosis of IDD requires that individuals experience some degree of impairment that influences their intellectual and adaptive functioning (13-14). Intellectual functioning is determined by a person’s ability to learn, as assessed through standardized tests. On the other hand, “adaptive functioning” is an umbrella term that encompasses three distinct types of skills, each of which focus on a person’s ability to engage in activities related to everyday life. The three skill groups relevant to adaptive functioning are: 1) conceptual skills (e.g., reading, math, reasoning, language, memory), 2) social skills (e.g., interpersonal skills, friendship-building abilities, social judgment), and 3) practical skills (e.g., recreation planning, financial management, personal care, organizing tasks) (13).

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[1] Throughout this article, I use the term “healthcare provider” (HCP) with the intention of encompassing a broad range of professionals, including but not limited to regulated professionals (e.g., physicians, nurses, occupational therapists, behaviour analysts) and non-regulated professionals who support persons with IDD (e.g., direct support professionals, personal support workers).

[2] It should be noted that different legislative frameworks and resources may exist to help HCPs navigate risky decision-making and/or potentially dangerous circumstances depending on the jurisdiction within which they are working. Generally speaking, respecting a person with IDD’s self-determination is prioritized, but different legally required responses to certain types of decisions may exist depending on the local context.

[3] A risky decision may also be influenced by a host of other non-trust-related factors, but lack of trust is at least one significant factor that may motivate certain kinds of decisions to be made.

Diagnoses of IDD are more prevalent in developing nations because of “more frequent injuries at birth, childhood brain infections, and iodine deficiency” (4, p.5). IDD is also caused by genetics (e.g., Fragile X syndrome, Down Syndrome) and prenatal exposure to alcohol resulting in Fetal Alcohol Spectrum Disorder (FASD) (4).

As highlighted by the American Association on Intellectual and Developmental Disabilities, it is important to emphasize that people with IDD are a heterogeneous population (14); every person with IDD will have different challenges, strengths, presentations, capabilities, and experiences associated with their disability. Relatedly, the amount and degree of support that a person with IDD may require to navigate and enhance aspects of their life will differ.

It is well-known that there exist health discrepancies amongst people with IDD when compared to others, and that members of this population tend to die at younger ages than the general population (3-9). Obtaining concrete, up-to-date, and evidence-based data related to morbidity and mortality rates for people with IDD is difficult. However, some informative reports do exist. One of the most comprehensive reports comes from the UK’s LeDeR service improvement program, which reviews health and social care data to determine where gaps exist in relation to health outcomes and deaths of people with IDD and autistic people[4] (16). At the time of writing this article, the most recent LeDeR report available reflects upon 2022 data, in which the LeDeR team reviewed files of 3648 people with IDD and/or those on the autism spectrum who died.[5] The report notes that most deaths of people with IDD (57%) occurred in hospital, which is a greater percentage than the general population. The most frequently reported causes of death related to the following categories (which align with ICD-10[6] chapters): “diseases of the circulatory system, diseases of the respiratory system, neoplasms, diseases of the nervous system, congenital malformations, deformations and chromosomal abnormalities” (5, p.44). These causes of death accord with what is stated in other reports. For instance, in Balogh et al.’s 2016 Cochrane review, causes of mortality for people with IDD commonly included, “neoplasms, and respiratory, cardiovascular and nervous system diseases” (4, p.5).

Notably, deaths by COVID-19 were higher in people with IDD than those without. An additional difference amongst those with and without IDD is that while “[c]ongenital malformation, deformations and chromosomal abnormalities were the first leading cause of death for people with a learning disability in almost every English region in 2022”, the leading cause of death of the general population was dementia and Alzheimer’s disease (5, p.51). Finally, between 32% and 45% of adults with IDD also have a mental illness, which is frequently referenced as “dual diagnosis” (4). Dual diagnoses are becoming increasingly prevalent and may also result in hospitalization (17).

In short, it is known that people with IDD have significant health needs, and that some of these needs may differ in terms of prevalence, complexity, and presentation when compared to those without IDD. People with IDD require health care services and hospital admissions, and relevant ethical dilemmas are bound to occur.

ETHICAL DILEMMAS: CONSIDERING AUTONOMY, DIGNITY OF RISK, AND IDD

When a person with IDD is admitted to hospital or requires care provision in the community, it may be the case that an ethical dilemma(s) arises. As stated in the Introduction, ethical dilemmas occur when there is a tension or conflict amongst at least two competing ethics principles. Although several ethical principles and values are relevant to care provision, four of the most frequently cited principles come from Beauchamp and Childress’s four principles approach to healthcare ethics: autonomy, beneficence, non-maleficence, and justice (11). Beauchamp and Childress are clear in their intent *not* to prioritize any of the principles. Rather, when principles conflict such that an ethical dilemma arises, they argue that one ought to engage in a weighing and balancing act to determine how to proceed (11).

Although the four principles are not weighed in any hierarchical manner, it is frequently the case that the principle of autonomy is prioritized in Western liberal societies.[7] Generally speaking, the principle of autonomy suggests that we ought to respect individuals’ decisions in relation to themselves. Historically, the concept of autonomy focused on the idea of “self-governance” and reflected on capacities associated with “self-made men” (19). The concept has since evolved, and various conceptions of autonomy now exist (20). While recognizing that these different theories exist, I use the term “autonomy” throughout this article to refer to general circumstances in which a capable person makes a decision in relation to themselves about care provision. Philosopher Dan Callahan considers why autonomy is often prioritized and says that “[a]utonomy is… given a place of honour because the thrust of individualism, whether from the egalitarian left or the market-oriented right, is to give people maximum liberty in devising their own lives and values” (21, p.289). In other words, the notion of individual liberty, i.e., the freedom to make decisions in relation to oneself, is immensely valued in certain societal contexts.

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[4] I recognize that differences exist amongst person-first vs. identity-first language. At the time of this publication, and based on the place within which I am situated and the literature consulted, identify-first language when speaking about those in the autistic community is generally preferred. I appreciate that there exists differing individual, organizational, and national perspectives and respect these choices.

[5] As indicated in the report, the people included in this review were those “aged 4 and above with a learning disability, and autistic adults aged 18 years and above...” (5).

[6] The ICD-10 stands for the “International Statistical Classification of Diseases and Related Health Problems 10th Revision” (18).

[7] The rationale for focusing on Western societies is because of where I studied and am presently situated as a clinical ethicist. However, it is important to acknowledge that the way in which these principles are prioritized and realized in Western societies do not nor should not necessarily reflect the priorities or practices of people who are located in other contexts.

As noted above, the principle of autonomy generally suggests that we ought to respect a person's decision(s) irrespective of the decision itself.[8] Whether one's decision is — from some perspectives — good, wise, safe, risky, ridiculous, etc. is often irrelevant. A person's autonomous decision ought simply to be respected. There are a few different ways that autonomous decisions are realized in practice. In healthcare settings, one way that autonomous decision-making is realized is through the practice of consent (or refusal) to a proposed healthcare intervention. If a healthcare intervention is proposed by a clinician, then a patient can express their autonomous decision in relation to the proposal by consenting or refusing. If a patient is capable[9] of consenting or refusing to a proposed healthcare treatment, then not only would respecting their decision be legally defensible, it would also be ethically defensible as justified via the principle of autonomy.[10]

The principle of autonomy offers a rationale as to why healthcare service users should have their risky (or at least seemingly risky) decisions respected. Depending on a person's individual values, beliefs, preferences, culture, life experiences, etc., they may make decisions regarding care provision that are "risky" or "wrong" from certain standpoints, including from the perspective of HCPs. For instance, suppose a person is diagnosed with a form of cancer that can be cured through a surgical intervention, but the person refuses to consent to the surgery. This refusal to consent is the way that the patient's autonomous decision is expressed, and while it may seem like an absurdly risky, wrong, and somewhat irrational decision from the perspective of the surgical oncologist, the principle of autonomy would presumably lead the surgeon to respect their patient's decision.[11]

When thinking about autonomous risky (though not necessarily dangerous) decisions and people with IDD, a further, related, concept is sometimes used to help HCPs justify the decision to respect a person's autonomous risky choice. That concept is the "dignity of risk." The dignity of risk was introduced by Robert Perske in 1972, and it describes the importance of offering and allowing people "to assume a fair and prudent share of risk" in relation to their capabilities (12, p.24). Perske notes that what it means for a person to lead a dignified life may require some degree of risk-taking. As such, entirely preventing a person with IDD from making an autonomous, risky decision may negatively influence their dignity. In other words, insofar as a person with IDD's dignity is important, then so is respecting their autonomous risky decisions. The dignity of risk has been considered in relation to other populations, where it has been found that allowing people in positions of vulnerability to make autonomous risky decisions can lead to an improved quality of life (22).

In sum, the principle of respect for autonomy — and the related concept of dignity of risk — are often used to support the ethical defensibility of allowing people with IDD to make and follow through with risky decisions. These concepts provide a rationale as to why people with IDD should be able to make risky decisions without unwanted and undue paternalistic interference from HCPs. Relatedly, the principle of autonomy and the dignity of risk may help HCPs better understand and respect a person with IDD's decision to refuse to consent to a recommendation or lead a particular kind of life. In order to consider the way in which the principle of autonomy and the related concept of dignity of risk may influence care provision for a person with IDD, the following section introduces a case example.

CASE SCENARIO: PRIORITIZING AUTONOMY AND THE DIGNITY OF RISK

Adhi[12] is a 45-year-old male with diagnoses of mild intellectual disability and generalized anxiety disorder. Adhi lives with his older sister, his primary support person, in a 3-storey walk-up apartment building. His father works abroad and his mother recently died. Adhi sometimes engages in property destruction and aggression toward his sister. Adhi does not have a family physician and uses the emergency department when care is required.

Recently, Adhi's sister came home from work and found him on the floor after what looked like an episode of property destruction. She called 911 and Adhi was admitted to hospital. Shortly thereafter, Adhi was diagnosed with a cardiovascular condition. Furthermore, the clinicians suspected a dementia diagnosis, which affects people with IDD (particularly those with Down Syndrome) younger than the general population (23-26). Adhi was described as "behavioural" while in-hospital — he frequently tried to exit-seek, hit the staff when they tried to check his vitals, and was eventually placed in physical restraints.

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[8] I recognize that accounts of substantive autonomy would disagree with this description. However, as mentioned, I am using the term "autonomy" in relation to how it is typically used in clinical practice, where — rightly or wrongly — a capable person's decision, irrespective of what it may be, is typically referenced as "autonomous".

[9] What it means for a person to be "capable" will differ depending on the jurisdiction within which a person receives care. In my setting, in Ontario (Canada), capacity requires a person to understand the treatment being proposed and appreciate the reasonably foreseeable consequences associated with consenting or not consenting.

[10] It ought to be noted, however, that autonomy is not synonymous with capacity, and a person may be able to express an autonomous preference or decision even if they are not regarded as capable from a legal standpoint.

[11] It should be noted that a "risky" decision may not necessarily be "dangerous". To determine whether a risky decision is dangerous, it is necessary to evaluate the severity and likelihood of a person experiencing certain harms. For instance, suppose a patient does not consent to recommended surgery after going through an informed consent process. In this case, there may be a risk of experiencing certain harms, though the patient would not be in danger, per se. However, suppose a patient whose capacity fluctuates is *not* recommended for surgery and informs their care team that they plan to travel (which is not recommended due to the state of their illness) alone to another country because they found a surgeon online who can cure them with surgery for $500,000. In this case, the significance, likelihood, and severity of the possible risks of harm may lead a HCP to determine that the decision is dangerous. When a person is likely to experience danger, it may be considered defensible to attempt to sway their decision-making and potentially infringe on their autonomy to a greater extent than would otherwise be the case. Furthermore, there are likely relevant legislative frameworks that can support HCPs in managing dangerous decisions.

[12] This is a fictional case, though aspects of it are drawn from my experiences as a clinical ethicist.

When Adhi was clinically stable, his HCPs developed a proposed plan of care for discharge. They discussed their recommendations with Adhi and his sister. Recommendations included medications to manage his cardiovascular condition, a referral to a neuropsychiatrist to verify suspected dementia, as well as personal support workers to help him with some activities of daily living with which he struggled. Behaviour therapy was also recommended to support anger management. Unfortunately, other than behaviour therapy (which he received in his early adult years), Adhi was adamant about not taking medications, not wanting anyone to help him with daily activities, nor wishing to see any other doctors. Adhi communicated his desires consistently and would not change his mind, even with his sister's decision-making support. He kept saying "no".

The clinicians on Adhi's team were appropriately trained to presume capacity irrespective of disability, and they did not believe that there was any reasonable ground to deem Adhi incapable of consenting (or refusing to consent) to their recommendations. Furthermore, even if Adhi were incapable, the team realized that Adhi was communicating a clear and consistent preference, and would be unlikely to open the door for HCPs or attend appointments even if such referrals were made with substitute/surrogate consent. The clinical team were trained to respect a patient's autonomous preference even if it was risky. They had also recently attended rounds where the concept of "dignity of risk" was introduced, and they appreciated that infringing on Adhi's risky autonomous decisions may infringe his dignity as well. Based on this, they respected Adhi's risky decision to be discharged without their recommendations in-place.

In this scenario, Adhi's decision to refuse to consent to most of the recommendations was regarded as risky. This risky decision was respected because it was regarded as autonomous and potentially relevant to his dignity.

From some perspectives, respecting Adhi's autonomous risky decision may be entirely ethically defensible, particularly given the significance of autonomy and the dignity of risk. For those HCP who may be uncomfortable with the riskiness of the decision, and the fact that Adhi could — if his decision were different — presumably have a better quality of life, they may consider implementing a risk mitigation approach. Ultimately, however, it is plausible that Adhi's decision would be honoured due to the idea that respect for autonomy ought to be prioritized.

A DIFFERENT APPROACH: DEMONSTRATE TRUST, THEN RESPECT FOR AUTONOMY

Respect for autonomy is an immensely important principle, as is the related concept of the dignity of risk. In particular, the principle of autonomy may be of particular significance when working with populations who have experienced historical oppression, been subjected to unjustifiable paternalistic practices, and whose autonomy has not, consequently, been respected. Many people with IDD fit into each of these categories. The purpose of this section is not to contest the importance of respect for autonomy when working with people with IDD in and of itself. Rather, the aim is to encourage a justified pause in advance of respecting a person with IDD's autonomous risky decisions. The pause is to prioritize, before respecting autonomy, the demonstration of trustworthiness by HCPs. More specifically, I argue that *only* insofar as HCPs take the time to intentionally demonstrate trustworthiness should a person with IDD's autonomous risky decision be respected; this is because trustworthiness may influence trust, and trust influences decision-making.

Trust and trustworthiness are complex philosophical concepts, and different definitions and theories exist. Common to these is the view that trust in one's HCPs, or lack thereof, has the potential to influence individual patient decision-making in some way, shape, or form (27-30). For instance, a 2004 study conducted by Mainous III et al. explored "the relationship between continuity of care and trust with a primary care provider with stage of cancer diagnosis among a sample of patients newly diagnosed with breast or colorectal cancer" (27, p.36). The researchers found that there was a "significant association between cancer stage at diagnosis and physician trust…" (p.38). They note that "[a]ccess to care and trust in a physician, rather than continuity, may be the key to increasing early detection of cancer in primary care practice" (p.39). Although not stated directly, the research findings suggest that a patient's trust in and relationship with their primary care physician influenced cancer screening decision-making.

A meta-analysis by Birkhauer et al. (31), conducted to explore the relation between health outcomes and trust in health professionals, found a significant correlation between higher trust in health professionals and patient satisfaction. They also found a smaller, though important, correlation between trust in health professionals and beneficial health behaviours, higher quality of life, and less symptoms associated with health conditions, presumably due to patient decision-making amongst those who trust their providers. For instance, if a patient trusts their provider, they may be more open to accept treatment recommendations that support improved symptom management and quality of life. In short, trust matters, trust influences decision-making, and an HCP's trustworthiness may influence the degree to which they are trusted.

It may be the case that trusting HCPs is relatively straightforward for some individuals irrespective of an intentional demonstration of trustworthiness on the part of HCPs. One conception of trust comes from Annette Baier who notes that, "[r]easonable trust… require[s] good grounds for such confidence in another's good will, or at least the absence of good grounds for expecting their ill will or indifference" (32, p.235). Baier's account of trust can be applied to various environments. When it comes to health environments, this suggests that insofar as there is reason to believe that a HCP has good will toward a patient, then the patient would consider the HCP trustworthy. In other words, if there is *not* a reason for expecting a HCP to have ill will, then the patient would have grounds for reasonable trust. When working with many patients in healthcare, reasonable trust may be immediate and inherent to the clinical context. Many, if not most patients may be aware that their care requires HCP support, know about HCP training and expertise, be cognizant of HCP codes of ethics and practice standards (which require that patients are cared for in certain kinds of ways) and, relatedly, have grounds for expecting that clinicians have good will toward them. Consequently, these patients may find HCPs to be trustworthy simply by virtue of them being HCPs, and this trust may influence decision-making processes and outcomes. For example, in an environment in which HCPs are inherently trusted, patients may be more open to engaging in dialogue about treatment recommendations and meaningfully contemplating such recommendations based on the perspective that the HCP is necessarily well-intentioned.

On the other hand, when working with some populations, such as patients with IDD, reasonable trust may not exist, at least not inherently. Many patients with IDD may *not* have grounds for expecting that HCPs have good will toward them. In fact, there may be grounds for them to expect ill will or indifference from members of their clinical team. For instance, there exists a relatively recent history in which infants with Down Syndrome were denied life-saving treatment based on HCP biases related to the kinds of lives worth living (and saving) (33-34). Furthermore, within the last century, unethical medical experimentation was conducted on people with IDD. One of these experiments occurred between 1946-1953 by Harvard University, MIT, and the Quaker Oats Company. As described by Merrick, this experiment:

> expose[d] young male children aged 10-15 years with IDD to tracer doses of radioactive isotopes. The boys were encouraged to join a "science club", which offered larger portions of food, parties, and trips to Boston Red Sox baseball games. Once inducted, club members ate iron-enriched cereals and calcium-enriched milk for breakfast. In order to track absorption, several radioactive calcium tracers were given orally or intravenously. Radiation levels in stool and blood samples would serve as dependent variables. Neither the children nor their parents ever gave adequate informed consent for participation in a scientific study. In a 1995 class-action suit the victims were awarded a $1.85 million settlement from MIT and Quaker (35, p.2202-3).

Additionally, women with IDD were commonly, involuntarily sterilized for much of the twentieth century (36) and continue to experience pressure to use contraception or to have their reproductive rights restricted based on ableist societal and HCP beliefs about who should and should not parent (37-38). Relatedly, when people with IDD are pregnant, they experience pressure to terminate the pregnancy (39).

In general, receiving care based on ableist stereotypes and experiencing discrimination has been and continues to be commonplace for many people with IDD (40-44). In 2013, Ali et al. (41) investigated the potential discrimination experienced by people with mild or moderate IDD in accessing health services. Qualitative interviews were conducted with people with IDD, as well as carers of people with IDD. Although some positive experiences were highlighted, several detrimental experiences were also noted, each of which may reasonably influence a person with IDD not to find HCPs trustworthy. For instance, some of the interviewees described feeling "ignored by clinicians during consultations or 'were talked over' if their carer was present" and "[h]alf the participants thought that the patient had been discriminated against or treated poorly because of their intellectual disability" (41). In one of the individual interviews, a participant described an experience in which their legs were put in stirrups for an operation, but an informed consent process was seemingly not followed, as the person did not know the rationale for this action and what was happening to them. As a consequence of this experience, their carer noted that the patient "'feel[s] pressurised by [healthcare providers] ... he's had the operation, it hasn't worked. Now they're saying that they want to do it again. And he never went to the last appointment because he felt they were going to bully him into doing it'' (C15; mother). In short, given the historical and continued oppressive, ableist, and discriminatory practices experienced by people with IDD in healthcare environments, it may be the case that at least some people with IDD would not find HCPs to be inherently trustworthy. In fact, HCPs should assume that reasonable trust does not and should not exist. There are few reasons why people with IDD would have "good grounds for such confidence in a [HCP]'s good will" (32, p.235) if they have been subjected to any of the above experiences.

Insofar as HCPs' demonstration of trustworthiness may influence trust, and trust in HCPs can influence patients' decisions, then so can lack of trust. In reflecting upon the case of Adhi, it may be the case that he experienced discrimination and ableism in prior healthcare interactions. It is also possible that the healthcare team may not have communicated with Adhi in a way that optimized his decision-making process (which may have demonstrated an interest in his good will), as providers are seldom trained on how to work respectfully with patients with IDD (45). Ultimately, it seems possible (and is concerning) that Adhi's risky decision may have been influenced by his lack of reasonable trust in HCPs. Furthermore, the HCPs may *not* have intentionally demonstrated trustworthiness in attempt to gain reasonable trust. Adhi's autonomous decision not to consent to most of the team's recommendations may have been influenced by the fact that he had reasonable grounds to believe that his best interests were not in the team's heart. So, under what circumstances would it make sense for him to consent to HCP recommendations? It would not — unless there is trust.

When working with people with IDD, it is incumbent on HCPs to first assume that a lack of trust exists and then intentionally demonstrate trustworthiness. Trustworthiness may influence trust, and trust influences decision-making. If a patient with IDD makes a risky autonomous decision in an environment where they do not find their HCP to be trustworthy, then it may be the case that this decision was influenced by lack of HCP trust. In other words, it is possible that a different autonomous decision may have been made if trustworthiness was demonstrated, and if trust existed. This aligns with literature related to increasing compliance with treatment interventions, where a patient's experience of empathy and compassion from their HCPs (which are relationship- and presumably trust-building factors) may influence patient compliance (46). Of course, it ought to be stated that there are other reasons as to why a patient may not consent to treatment recommendations and/or make a seemingly risky autonomous decision. In the case of Adhi, for instance, it may be that medication texture, physical discomfort, or other factors were the primary and/or another reason as to why he refused to consent to the recommendations. However, when working with people with IDD, not finding their HCP trustworthy may very well influence decision-making in at least some circumstances.

With the above being the case, it is reasonable to suggest that if a person with IDD makes a risky decision in an environment in which trustworthiness has been demonstrated, and trust may exist as a consequence, then HCPs can feel more confident that the person's risky decision is truly autonomous and in accordance with their conception of dignity. If a patient makes an autonomous risky decision before their HCP demonstrates trustworthiness, then it may not *necessarily* be the case that the decision accords with their conception of dignity (nor, from some perspectives, is necessarily autonomous) since there may not be trust.

POTENTIAL OBJECTIONS

Objections may be raised in response to the above. Adhi's initial decision might not, in fact, be autonomous. As mentioned at the beginning, there exist different conceptions of autonomy. It is plausible that supporters of procedural autonomy (which focuses on the decision-making process in determining whether a decision is autonomous) and substantive autonomy (which focuses on the substance/content of the decision in determining whether it is autonomous) may argue that Adhi's refusal to consent to the recommendations was not an autonomous decision. This may be true. However, insofar as the principle of respect for autonomy does not hold any particular theoretical leaning in healthcare environments, then Adhi's initial risky decision would likely be considered autonomous and respected, regardless of whether it is made in an environment of trust (or in accordance with particular philosophical conceptions of autonomy). This is the primary reason that I argue for a pause to demonstrate trustworthiness in advance of respecting a person with IDD's autonomous risky decision. Trustworthiness may be demonstrated by building rapport, providing care with empathy and compassion, and caring for a person with IDD's from a place of good will (46). Trustworthiness may influence a person with IDD's degree of trust in their HCP, which may subsequently influence their autonomous decision, but the decision would presumably be respected either way as justified by the principle of autonomy in healthcare.

An additional concern about requiring the demonstration of trustworthiness before respecting a person with IDD's risky decision is that the process required to demonstrate trustworthiness could be seen as infringing on a person's autonomy and/or as somewhat paternalistic in nature. For instance, if HCPs prolonged Adhi's discharge so that they could demonstrate trustworthiness (with the hope that he may trust them and make a different decision), then this would prevent Adhi from being discharged in a timely manner and in accordance with his clearly expressed wish. However, in response to this concern, it ought to be stated that the primary purpose of establishing trustworthiness is *not* to alter a person's risky decision so that it becomes less risky. The aim is to create an environment in which a person with IDD's risky decision is not unduly influenced by lack of trust in their clinical team because trustworthiness has not been intentionally demonstrated. Additionally, insofar as the demonstration of trust is prioritized when working with people with IDD, then HCPs would and should strive to demonstrate trustworthiness well in advance discharge-related discussions.

CONCLUSION

In Western liberal societies, the principle of autonomy is often prioritized above other ethics principles in healthcare settings. The way that autonomy is typically respected is through a patient's consent or refusal to consent to a proposed healthcare treatment. Given the significance of autonomy, it is frequently the case that if a patient makes an autonomous risky decision, then the decision is considered justified by the principle of autonomy. And when it comes to people with IDD, respecting autonomous risky decisions is further justified by the concept of the dignity of risk.

It is known that patient decision-making may be influenced by the trust they have in their HCPs, where "[r]easonable trust… require[s] good grounds for such confidence in another's good will" (32, p.235). Importantly, HCPs' demonstration of trustworthiness may influence trust. Based on historical and continued ableism and discriminatory practices in healthcare settings, at least some people with IDD may not have reasonable grounds to trust their clinicians. This means that some patients with IDD who make autonomous risky decisions may be motivated by lack of trust; they may (or may not) have made a different decision if they trusted their HCP based on their HCP's demonstration of trustworthiness.

Given the importance of respect for autonomy and the way that autonomous decisions are influenced by trust, it is essential for HCPs to demonstrate trustworthiness when working with patients with IDD in advance of respecting an autonomous risky decision. In other words, before respecting a person with IDD's autonomous risky decision, HCPs should pause and ensure they are intentionally demonstrating trustworthiness from which a person with IDD may be more likely to trust them. If care providers demonstrate trustworthiness effectively then (a) the patient may be more likely to make a decision that aligns with providers' recommendations because they trust that the provider has good will or (b) a risky decision may still be made, and care providers can have increased certainty that the decision is truly autonomous and in accordance with the person's conception of dignity. Both outcomes are preferable to unquestioningly respecting a patient's risky autonomous choice.

There are some relatively straightforward strategies that HCPs can employ to demonstrate trustworthiness when working with people with IDD. For instance, taking the time to find out how a person with IDD most effectively communicates (verbally, using visual aids, etc.) and then communicating accordingly may be one way to demonstrate good will. There are likely many other methods that HCPs can employ to demonstrate trustworthiness with this population, though further research on this topic may also be of benefit. The purpose of this article is not to show how to demonstrate trustworthiness, but rather to argue that HCPs ought to employ whatever methods exist (e.g., rapport building, empathy, and compassion) prior to respecting a person with IDD's autonomous risky decisions. Demonstrating trustworthiness in an attempt to gain trust matters.

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