Sector Pandemic Planning Initiative

Ethical Decision-Making Framework for Developmental Services

Introduction

Caring in normal circumstances within the DS sector is fraught with many ethical challenges, the variety of which can be summed up in the following way: balancing the duties of care with the dignity of risk. In extraordinary circumstances, myriad ethical challenges are magnified both in terms of their urgency and their complexity. Whereas it is necessary to have access to an ethical framework for making ethical decisions in general, in times of crisis that necessity obtains a certain gravity. Those responsible for supporting the health, safety, and well-being will find themselves faced with a number of complex moral dilemmas that stretch their capacity to substantially identify, assess, and judge what constitutes the right course of action. A framework for ethical decision making can serve to ease this process while also increasing accountability, transparency and procedural uniformity.

The following framework provides:

- A way to identify ethical tensions in relation to concrete cases
- A way to determine which should be given priority
- A way to arrive at a concrete, justifiable decision
- An example of how an ethical issue can be identified, resolved, and operationalized -> *the right of DS direct care workers to refuse work*.
- A glossary of fundamental ethical principles and values

Part I

Ethical Decision-Making Framework

1. Identifying the problem

A. Identify all relevant facts of the case
- Who is involved - what is their status in a network of relationships, what is their bio-psycho-social status, what is their character, what are their desires, beliefs, thoughts?
- What is the state of affairs - what has happened, is happening, will continue to happen?
- What is the cause of this state of affairs - presence/absence of structures, personnel, procedures?
- Establish as much evidence for each of the above as possible, being transparent with the quantity and quality of this evidence

B. Identify all relevant ethical principles and values the case involves
- List as many as you can
- Identify the most relevant from the list
- Rank them in importance (e.g. 5 = essential; 3 = significant; 1 = minor)

C. Identify which principles/values are in tension and why
- Typical tensions include, but are not limited to:
  - Beneficence and nonmaleficence
  - Utility and justice

- Autonomy and privacy
- Privacy and vulnerability
- Consent and care
- Rank the importance of resolving these tensions from greatest to least

2. Creating a solution

A. Questioning
- Revisit the list of principles in tension and pose some "*how might we … ?*" questions:
  - … best support direct care staff who are encountering increased risk of harm at work because of COVID-19? (Beneficence and nonmaleficence)
  - … support the decision-making of the IID/IDD individuals under our care in the face of lockdown restrictions? (Consent and care)

B. Recommendation
- Identify again which principles/values should overriding consideration
- Identify how those principles/values that cannot be given priority should still be promoted as much as possible
- Articulate a recommendation for action
- Articulate a justification for this recommendation

3. Operationalization

A. Operationalize your recommendation
- How can we apply our recommendation to achieve its objective?
  - Flow chart - create a chart that maps viable ethical solutions to a set of relevant problems direct care staff regularly encounter in the field
  - Policy - articulate your recommendation in terms of rules and regulations
  - Education workshop - invite all relevant stakeholders to participate in a workshop to build the desired capacities of your recommendation

B. Evaluate your operationalization
- What is the criteria for judging successful operationalization?
  - Does it uphold the principles/values we've prioritized? (Rank: 5 = very well, 3 = well, 1 = poorly)
  - Is it practical?
  - Is it reliable? (Rank)
  - What could be improved? (feedback)

C. Revise, reintroduce and reevaluate (ongoing)

Glossary of Ethical Principles and Values

- **Accountability** - To be responsible for something or to someone on account of your status in the relationship you have to it or them

- **Autonomy -** Individual capacity of self-determination, informed decision-making, and informed consent. Autonomy is dignity-granting and demands respect; i.e. cannot infringe on or restrict autonomy without good reason. *Paternalism* = overriding another's decision making for their own good; *weak paternalism* may be compatible with *weak agency.*

Relational autonomy is the idea that agency is always codependent, so decisions are made in relation to, and with the support of others

- **Beneficence -** To provide benefit to another by promoting their welfare to the extent possible and permissible

- **Consent -** To agree to do something or have something done to you. Depends on relative capacities of communication, understanding, appreciating, formulating and expressing desires, beliefs and thoughts. See *supported decision making*

- **Duty of Care -** Observation of our responsibility to avoid, minimize or mitigate against harming another, and to promote their well-being as far as possible and permissible. Care involves responding to the needs of others in the way they determine them

- **Integrity -** To have a coherent and consistent set of moral principles and to abide by them even when interests run contrary to such principles

- **Justice -** To be fair (i.e. treating equals equally) and reasonable in action, to establish an equitable state of affairs, restoring to equity an unfair or unreasonable state of affairs
  - **Fidelity -** The quality of being faithful to someone or something, conducting oneself 'in good faith'; i.e. in a trustworthy, honest fashion
  - **Inclusivity -** To equally incorporate all relevant stakeholders in the communication and creation of policies and to provide for equal access to basic resources and services, as well as the equal opportunity to obtain goods
  - **Reciprocity -** To realize mutual benefit in an exchange, to return in kind to another what was given to one

- **Nonmaleficence -** Prohibition on intentionally *harming* another. Duty to do no harm restricts the autonomy of others

- **Privacy -** An extension of autonomy, privacy is a state free from interference with, monitoring of, or unwanted disclosure of personal information one wishes to keep rightfully confidential

- **Proportionality -** The quality of understanding and appreciating relevant facts, values and interests of differing degrees of importance, and to achieve a just balance of these in decision-making

- **Reasonable -** A moral decision should not be based on merely on a hunch, intuition, belief, or feeling, but should be the product of *principled deliberations* whose justifications are able to be clearly communicated

- **Respect/Dignity -** To be regarded with admiration because of who one is or what one has done - to have *dignity* is to be an object of respect not because of who one is (socially) or what one has done, but because of *what someone is* - i.e. *persons* are to be treated with *dignity* regardless of social status or achievement

- **Responsibility -** A) an act that you are not at liberty not to do; i.e. even if you don't want to, you are obligated to do this. B) a role in a relationship where you are charged to execute

- **Rights -** The entitlement to some benefits and the protection against some harms that safeguard fundamental human interests

- **Supererogatory -** A moral act that is not obligatory; i.e. you may confer benefit if you want, but you are not responsible to do so

- **Supported Decision-Making -** decisions made in consultation and collaboration with another that understands, appreciates, respects the desires, goals, character traits, values, beliefs, traditions, and relationships, and seeks the welfare of that other. Inverse proportion of capacity and supported decision-making: increased capacities = less support / decreased capacities = increased support

- **Transparency -** The quality of being honest, forthright, and open in the process one has enlisted to arrive at a decision

- **Trust -** The quality of being reliable and accountable; having confidence in someone or something because they demonstrate reliability and accouontability

- **Utility -** To act in order to realize the greatest benefit while avoiding the greatest harm

- **Vulnerability -** To be susceptible to harms; especially because of ones bio-psycho-social status

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Part II

Ethical Issue in Focus: The Right to Refuse Dangerous Work

I. Identifying the problem

Who is involved:

Direct care staff, the persons under their care, and the vast network of relationships that each brings to the context of direct care.

What is the state of affairs:

Increased danger in the workplace due to public health crisis (pandemic influenza virus).

It does appear that a directly proportional relationship has emerged between the degree to which one is immunocompromised and the risk of severe impact, and that this is strongly correlated with age.

It does appear that the virulence of the virus is, otherwise, in the mild range, while the transmissibility of the virus hovers in the moderate to severe range. Corresponding increase in DS agency direct care staff enlisting their right to refuse dangerous work.

The Occupational Health and Safety pamphlet defines *danger* in the following way: "*any hazard, condition or activity that could reasonably be expected to be an imminent or serious threat to the life or health of a person exposed to it before the hazard or condition can be corrected or the activity altered."*

It outlines, however, some exceptions to the circumstances that could constitute the necessary and sufficient conditions to refuse dangerous work: *"if the refusal puts the life, health or safety of another person directly in danger; or, the danger in question is a normal condition of employment."*

The nature of the support direct care staff provide within the DS sector places it within these *exceptional conditions*:

A) the care provided to IID/IDDs on behalf of the provider is of such a nature that, were it to be removed, the life, healthy or safety of the individual cared-for would be at risk (risk increases proportionately with the increasing degree of intellectual ability and adaptive functioning)

B) the normal conditions of employment in the DS sector involve varying degrees of risk.

Cause of this state of affairs:

- COVID-19 public health pandemic: state-sponsored and enforced shelter-in-place, physical distancing, quarantine, self-isolation, public space and non-essential service closures.

***THE* dilemma:**

Is it reasonable to think that COVID-19 poses an "*imminent or serious threat to the life or health of a person exposed to it*"? If so, is it permissible for direct care staff to enact their right to refuse dangerous work when such a refusal has the potential to harm those under their care?

Relevant Principles and Values:

- **Accountability**
- **Autonomy**
- **Beneficence**
- **Consent**
- **Duty of Care**
- **Justice**
- **Nonmaleficence**
- **Proportionality**
- **Reasonable**
- **Respect/Dignity**
- **Responsibility**
- **Rights**
- **Supererogatory**
- **Supported Decision-Making**
- **Transparency**
- **Trust**
- **Utility**
- **Vulnerability**

Most relevant principles/values ranked in importance (5 = essential; 3 = significant; 1 = minor):

5	3	1
Nonmaleficence	**Supported Decision-Making**	**Supererogatory**
Vulnerability/Responsibility	**Utility**	
Duty of Care	**Trust/Transparency**	
Beneficence	**Reasonableness**	
Rights	**Accountability/Proportionality**	
Autonomy/Consent		

Principles/values in tension:

1. Beneficence <-> Nonmaleficence - Rights
- The right of IID/IDD to realize the benefits of care stands in tension with the rights of direct care staff to avoid harms (i.e. life and security)

2. Nonmaleficence <-> Beneficence - Utility
- The disutility of the absence of the benefits of being appropriately cared for realized by the IID/IDD stands in tension with the utility the care worker would realize by minimizing risk of harm

3. Proportionality <-> Vulnerability - Duty to Care
- If the virulence of COVID-19 is moderate to high it may be a proportionate response to enact ones right to refuse dangerous work; but this would be to leave a responsibility to the cared-for unfulfilled. Given the status of having an increased susceptibility to harm in normal circumstances, IID/IDDs are left even more vulnerable if direct care staff refuse to work.

II. Creating a solution

How might we minimize the risk to direct care staff while still fulfilling the duty of care to IID/IDD? How might we do so while still respecting the direct care staff's right to refuse dangerous work while simultaneously respecting the right of IID/IDD's to the benefits of care?

Recommendation:

If an employee working in normal or *unexceptional* conditions encounters a danger warranting the exercising of their right to refuse work, the onus is on them to provide the evidence that working conditions constitute a danger so defined. The presumption of this mechanism is that employers are responsible to ensure reasonably healthy and safe working conditions. While this remains the case in *exceptional* working conditions, there is an increased burden of proof on the employee working in such conditions to prove that conditions have become ***exceptionally dangerous*****.** That is, **dangerous to the point where:**

A) **Normal conditions are so noxious that it would constitute an undue burden to expect anyone to endure them**
B) **The failure to confer the benefit of caring for individuals causes less harm to them than the failure to *not* exercise the right to refuse to work would cause the employee.**

Interpretation:

A) DS agencies have an obligation to ensure that **normal conditions are *not* so noxious that it would constitute an undue burden to expect anyone to endure them.** Given the evidence-based realities of COVID-19, agencies have a moral responsibility to come up with a uniform and structured set of health guidelines for observing proper hygiene. Though falling short of physical distancing (which, for obvious reasons, is not possible to fulfill in the care context) these measures should be observed in order to minimize the risk of contraction and spread of COVID-19. This would fulfill both a public and private health responsibility:

- **Public health:** this would decrease, to the extent possible, the transmissibility of COVID-19; since no one is at liberty to wantonly endanger anyone else, all reasonable measures should be taken to prevent such endangerment.
- **Private health:** DS agencies have an obligation to ensure the safest, healthiest environment possible for both direct care staff and the individuals under their care. To the extent possible, IID/IDDs should receive appropriate communication of relevant information, and be supported to consent to, and participate in, the measures that concern their health and safety.

B) When cases are presented wherein it is plausible that **the failure to confer the benefit of caring for individuals causes less harm to them than the failure to *not* exercise the right to refuse to work would cause the employee**, DS agencies have an obligation to support employees who enact their right to refuse dangerous work.

1. According to the present evidence: i) if an employee is, or is approaching, the age where increased susceptibility to severe impact is more likely, or, ii) if an employee has a chronic condition that would, because of comorbidity, increase susceptibility to severe impact, it would impose an undue burden on them to require them to continue to work. While all other direct care staff should view their caregiving activities as obligatory, staff who may be immunocompromised to a sufficient degree (i.e. as defined by a healthcare specialist), or iii) have a family member in their household who is at an increased risk, they *cannot* be made to feel equally obligated. Because of their condition, they now find themselves in the position of electing or not to engage in supererogatory act: to continue the benefit-conferring care of their clients or not.
2. Both (1) and (2) should be balanced by considering the “direct danger” to “the life, health or safety” of the IID/IDD that is under the direct care of the staff member. It goes without saying that DS agencies operate in the context of care - what does this mean? Care involves an obligation to be receptive to the needs of the cared-for. This imposes an obligation on the one-caring to appropriately respond to the needs of the cared-for. If the absence of benefit-conferring care resulting from the refusal to work is greater than the risk of harm such work would pose to the one-caring, the latter has a moral obligation to bring care to completion; i.e. according (1), the one-caring would yet find themselves in a position of fulfilling an obligation and not one of performing a supererogatory act.
3. If the actual care for IID/IDDs is being hampered because the one-caring is experiencing anxiety and stress, this is not beneficial for either the one-caring or one the cared-for. In addition to securing a safe and healthy workplace, DS agencies also have a moral obligation to address the mental health needs of their staff. Failure to do so would be a failure of the duty to care of agency leaders and would present an impediment for the care of the IID/IDDs under the care of direct care staff.

When is it right to enact my right to refuse dangerous work as a direct care provider in Developmental Services?