

Executive Functioning

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Informed Medical Consent. Is there a Role for Agencies and Their Staff?

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Another article on informed consent for treatment? We've heard all about it. We all know about it. Right? Maybe not.

If we all know about it, why are the principles of informed consent often inadequately applied? Maybe all of us – health care professionals, families, and support personnel could do better. As senior managers, what role can you play in ensuring that your agency and support staff are actively engaged in this process?

I realize that those of us who support people with developmental are sensitive to language. As a psychiatrist, I refer to all of the people I see in a professional capacity as patients which is the term I will use throughout this article.

Why is informed consent important?

Let's begin by asking why informed consent is important. Most importantly, it's the law. But wait a minute. Maybe that isn't why it's most important. Perhaps the most important reason for all of us to do better in the area of informed consent is out of respect for those to whom we provide care, support and treatment. Maybe that's why the law exists.

So why don't we do it well? Maybe we don't really understand the principles and how they are to be applied. Maybe we forget this crucial component of care in the heat of the moment because we are busy and time is short. Maybe, as will be discussed later, we make the mistake of assuming that everyone is competent.

But isn't informed consent something that doctors are responsible for? Is there really a role for agencies and your staff? It is true that at the end of the day, the person who is providing treatment is responsible for ensuring that informed consent has been obtained. However, there are ways that your staff can assist health care professionals in this. Before getting into how support staff can help, let's just review what informed voluntary consent is.

How is capacity for informed consent determined?

The usual criteria for capacity to consent to medical investigations and treatment include:

- the ability to understand the medical problem,
- the ability to understand the proposed treatment,
- the ability to understand the alternatives to the proposed treatment,

- the ability to understand the option of refusing treatment, and
- the ability to appreciate the possible outcomes from accepting or refusing the proposed treatment, including the benefits and risks of both receiving and not receiving the treatment.



Further, consent must be voluntary, and not obtained through coercion, misrepresentation or fraud.

Herein lies the first problem. How many of us, let alone those we support, really understand the jargon we are all exposed to day after day. While I consider myself competent, I once had an accountant who spoke so rapidly, and used so much technical language that it is highly doubtful that my consent for his actions on my behalf would be considered 'informed' – I subsequently changed accountants. With that in mind, let's put the previous paragraph in more concrete terms:

1. What treatment are you going to have?
2. Why are you having the treatment?
3. What will the treatment do for you?
4. Are there other treatments which might help?
5. What will happen if you don't have the treatment?
6. Are there any problems the treatment might cause?

If someone can satisfactorily answer all these questions, he/she likely has capacity for consent. Now before any of us could answer these questions, we would need to have information provided to us in a manner we can understand. Those we support may need additional assistance in this, and there is an important advocacy role for support staff here which will be discussed later.

Do persons with a developmental disability have the capacity for informed consent?

Ontario law states that a person is presumed to be competent *unless there is a reason to believe otherwise* (italics are those of the author). It is the last half of this statement which is often glossed over. How many of us have seen pieces of paper put in front of probably uncomprehending persons in order for them to scrawl some sort of mark under a presumption of capacity. Is it not true that there is often "reason to believe otherwise" in those we support? We become so focused on the presumption of capacity to consent, that we may forget that we might in fact be denying the right to informed consent to many of those who we support.

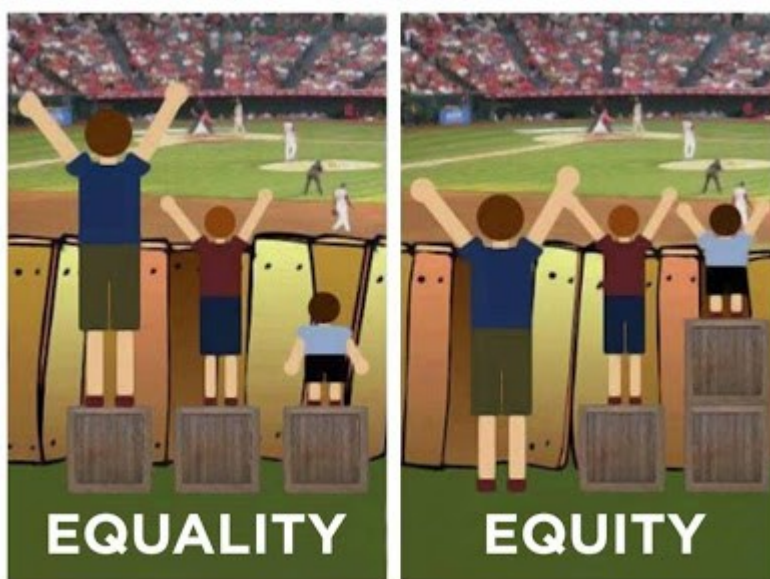
The following quote from reference 2 at the end of this article supports this more eloquently than I can:

".....it is another fundamental principle of ethics that all persons, insofar as they are persons, are equal and should not be discriminated against.[2] This is known as the principle of equality and justice. [5,7] It lies at the very heart of a just and fair society. Therefore, if someone cannot exercise her right to self-determination because she lacks the capacity to do so, then a just and fair society must provide some mechanism to compensate for this lack, lest she lose a right that belongs to all other persons

Or -- and potentially this is even worse -- if there was no mechanism to compensate for such a lack of capacity and the incompetent person did make a decision, then that decision would be treated as though it was competently made. While at first glance it might seem as though this respected the incompetent person's right, and while acceding to her wishes would indeed be to treat her in the same

way that all other persons are treated, that very sameness of treatment would actually amount to discrimination. Incompetent persons are not the same as competent persons precisely because they lack something that competent persons have: They lack competence.

To treat people who are not the same as though they were the same is just as discriminatory as treating people differently even though they in fact are the same. In each such case, what is done is ethically inappropriate. Good ethics, therefore, require not that people be treated the same, irrespective of their differences, but that they be treated equitably -- which means that their ethically relevant differences should be taken into account" [13] (Eike-Henner and Kluge, 2008).



Graphic adapted by the City of Portland Office of Equity and Human Rights from <http://indianfunnypicture.com/img/2013/01/Equality-Doesnt-Means-Justice-Facebook-Pics.jpg> via United Way of the Columbia-Willamette.

This consideration is crucial to the present context. It means that allowances must be made for lack of capacity, and that to honour the decisions of an incompetent person as though they were competently made would effectively be to punish them for their incapacity.

What proportion of persons with a developmental disability has capacity?

One study on capacity for informed consent in persons with developmental disabilities (DD) concluded that, most adults with a mild developmental disability and almost half with a moderate DD could at least partially understand information about the proposed treatment itself (i.e. could answer the first three questions above). However, there was much greater difficulty with the last three questions which require one to process information about pros, cons and alternatives in order to reach informed treatment choices - only "50% with mild, and 18% with moderate developmental disability were able to partially appreciate relevance of treatment choice to the person's situation and to weigh treatment risks against benefit" (Cea and Fisher, 2003). What do these numbers mean? There are in fact a substantial number of persons with a developmental disability who do have the capacity to partially, or even fully provide their own informed consent for at least some medical treatments. However, the numbers also mean that there is reason to believe that a substantial number of persons with a developmental disability lack capacity for informed consent. Our joint task is to distinguish, on a person to person basis, between these two groups else we risk depriving persons of their rights.

Just to complicate things further, we must also keep in mind that informed consent is not static. In other words, the same person may be capable to give informed consent at one point in time, but not at another; or, the same person may have capacity to give consent to one proposed treatment, but not to another. If a person is competent to give consent and we fail to involve them, we have failed to show them the respect they are due. In fact, if a person is competent to give his/her own consent and we do not seek this, we have broken the law. Even if a person lacks capacity to give informed consent and we do not involve him/her to the extent he/she is capable, we have also failed to show respect. If a person lacks capacity and we fail to obtain informed consent from a Substitute Decision Maker in the manner set out in legislation, we have broken the law. The Toolbook for Primary Care Providers (See Reference 3) contains a tool to assist health care providers in the process of ensuring that assessment for informed consent has been properly followed. Once again, although the ultimate responsibility for ensuring consent capacity has been determined rests with the health care provider, nonetheless, support staff can play an important role in facilitating this.

How often do discussions about treatment take place between physicians on the one hand, and families and support personnel on the other, over the heads of those who will be receiving the proposed treatment? How often do we stop to ask ourselves, “whether competent or not, has the identified patient been appropriately involved in the consent process?”

How can managers help?

What then is the role for agency executives and senior managers in the consent process? In short, educate and empower your front line staff who will be attending medical appointments with those they support. Until quite recently, medical training has ill prepared physicians (and other health professionals) to provide for the health care needs of persons with developmental disabilities. As a result, many physicians are uncomfortable in this field, and may lack awareness of how best to work with their patients who have developmental disabilities.

By their own communication with those they support, frontline support staff can model effective communication styles for the physician. Staff may be able to encourage physicians to interact directly with their patient rather than talking only to the care provider. Persons with developmental disabilities may have speech impediments. This can make it difficult for the health professional, who does not know them well, to understand what is being said. Frontline staff can often interpret. Because they generally know the person far better than the health professional, frontline staff may also be more aware of strategies which facilitate the person’s understanding. This of course raises a key operational issue for those in management – in order for support staff to be effective in this role, the patient should always attend medical appointments accompanied by someone who in fact does know him/her well. Not uncommonly, persons with significant disability attend psychiatric or medical consultation/ review accompanied by a care provider who has very limited knowledge of the person he/she is there to support.

Advocacy Role of Care Providers

I have mentioned the importance of the advocacy role for support staff. Are there any possible pitfalls in carrying out this function? In the earlier discussion of the criteria for capacity to consent, the necessity that consent be voluntary and without coercion was mentioned. When support workers assist someone in asserting his/her rights and choices about medical care, caregivers must be very aware of their own reactions to the proposed investigation or treatment. There is a risk that projection of the staff member’s own values may exert undue

pressure either for or against the proposed intervention rather than facilitating expression of the person's own opinions.

In addition, there are two sides to advocacy. On the one hand, staff can advocate ensuring that a person who has capacity is heard, is given relevant information, and is allowed to make his/her own choices. On the other hand, as noted above, advocacy also involves ensuring that a person who may lack capacity has a Substitute Decision Maker actively involved in the consent process. In addition, support staff can advocate that even those who lack capacity have still had interventions explained to them at a level they can understand.

Facilitation of Capacity

It has been shown that information about proposed investigations and treatment should be provided in small chunks, utilizing communication channels appropriate for that person such as visual aids, communication devices etc. Care providers need to ensure that these communication aids are always present for medical appointments and to assist the health professional in their use. Support workers can ensure that the patient has understood what has been said by encouraging those they support to repeat back, in their own words information provided by the doctor. This can help to avoid the risk that automatic affirmative responding on the part of the patient is mistaken for informed understanding. The information given must be tailored to the person's level of understanding. Informed consent is a dialogue amongst all players. Such an approach assists in the determination of whether any given person at a given time has consent capacity or not; in either case, such an approach respects him/her as the key player in the process.

When support staff use active listening with the persons with whom they are working, before, during and after medical appointments, this will provide additional opportunity for processing information and identifying preferences which can be related back to the health professional.

What about Substitute Decision Makers?

Since a substantial proportion of persons with developmental disability will lack capacity for consent to the current investigative or treatment proposal, managers need to educate their staff about the role of Substitute Decision Makers (SDMs). Ontario law spells out a hierarchy of potential SDMs, and consent must be obtained from the highest ranking eligible person (see www.surreyplace.on.ca/primary-care?id=135). **A paid care provider can never function as an SDM under Ontario law.** They can however convey information. Support staff should also:

- Be sure that everyone knows who the SDM is
- Be sure that the physician knows how to contact the SDM
- Better yet, if a person has a medical appointment that will likely require a new treatment, a change in treatment or investigations (especially if these would be invasive), consider asking the SDM to attend the appointment or arrange for the SDM to be available by phone so that the physician can make contact. (If there is an already previously agreed-to plan of care, this may not be necessary.)
- If the wishes of the SDM are known in advance, keep the health care professional informed.

In conclusion, although informed consent is ultimately the responsibility of health care professionals, its application should be a joint effort on the part of all concerned. While capacity should be presumed, we must always remember that there is often reason to suspect lack of capacity. By giving the principles of informed consent our careful consideration, we will do better in respecting the rights of those we support.

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