



# Involvement of Families and Carers is Essential in Provision of Involuntary Care to People with Intellectual Disability



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## Introduction

Provisions for involuntary care of a person with an intellectual disability exist in most jurisdiction-specific legislations around the world [1,2]. Many jurisdiction-specific laws have given Courts various powers to order detention and care of a person with a mental impairment who has been charged with or convicted of a criminal offence [3]. However, it is felt that for person who has not been charged, law does not provide sufficiently clear guidelines on when a person with an intellectual disability or a cognitive impairment can be treated without his or her consent [4]. A number of international frameworks and covenants also exist that provide guidance to ensure an individual's human rights are not disproportionately infringed [5-7]. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities [CPRD] requires specifically that supported decision-making regimes must be introduced, and that such schemes must respect the 'rights, will and preferences' of persons with disabilities [7] although a concern remains that involuntary care-related legislation does not always align with the intention in the CPRD [8].

An involuntary treatment of a person with intellectual disability is a legal process primarily to minimize the risk of harm to an individual and/or to the wider community. Involuntary care provisions allow care to be provided in absence of the person's expressed wishes or consent. This consideration is different in both nature and application to that related to health and treatment decisions made on behalf of the patients who lack the capacity or competence to make decisions. If the person lacks capacity to make decisions about their medical treatment, provisions exist in most jurisdictions for a substitute decision maker to provide

consent, however, when it comes to people putting themselves or other at risk by their actions, they can be deemed to be in need of involuntary care even if they have the capacity and competence to make decisions [9].

Many current legal provisions for involuntary care and treatment of people with intellectual disabilities also require family members and carers to be an integral part of decision-making process [10]. This must remain an essential consideration as many families care for their family members with intellectual disabilities for a considerable length of time before asking for help and assistance from caring services. Depending upon the perceived risk of harm to self and others and resources family members can invest in care of their loved ones, determine whether they can continue to support the unwell family member without use of involuntary care provisions.

## Balancing the needs of the person, the family and the community

Divergent views exist about use of involuntary care and treatment legislation to care for people with intellectual disability [11,12]. However, when consideration needs to be given to use of involuntary care and treatment, it is important to be cognizant of the fact that the needs of person with intellectual disability, their families and that of the community can be different. In using involuntary care provisions, it is important that autonomy and independence of the person with intellectual disability as well as concerns of family members about the safety and welfare of the person with intellectual disability inform the judgment about use of involuntary care provisions. The intention must always be to prevent any adverse outcomes for the person concerned.

In the process of accessing appropriate care for their family members with intellectual disability, it is not infrequent for families to feel conflicted. Families feel morally responsible to continue to provide optimal care and support to their family member even if the person who they care for does not understand, appreciate or accept care and support being provided to them.

Families can experience an internal conflict when making an application for compulsory assessment of the person who they care for. The interplay can be between wanting to respect the person's autonomy and acting in their best interest. While on the one hand, families may wish to continue to support their unwell family member and provide as much care to them as possible, on the other hand their concerns about risks and consequences [material or other] that the person with intellectual disability may present to themselves or to the families and the wider community, compels them to request compulsory treatment, despite knowing this may result in incarceration and deprivation of their liberty. By participating in the process that overrules the person's autonomous decision-making, they can also be perceived by the person with intellectual disability to be not acting in their interests.

Obviously, the need for involuntary care only arises when the management of risk of the person harming themselves or others is beyond the family or carers' capacity to manage. It then becomes necessary for them to seek help from caring services. Not infrequently families fear that requesting involuntary care for their family members may suggest to the person for whom care and support is being sought that the family is abandoning them, or do not wish to carry on bearing burden of responsibility of their care. Ongoing reassurance and support for the family throughout the whole process of involuntary assessment and care of the person with intellectual disability must remain on top of everyone's mind.

In the process of involuntary assessment and care, families can provide useful background and clinical information and a unique perspective having met the needs of their family member with intellectual disability over a prolonged period of time. From the very beginning of the assessment process, the intention should be to identify resources needed to assist the person with intellectual disability to manage the immediate risk, but also support families and carers who would need to provide care once the person's need for involuntary care is over.

Involuntary care can also be reassuring for the family as it provides a respite, often after many years of providing continuous care and ensures that their family member with intellectual disability is able to receive the care he/she needs. Even though an increase in risk or harm to self or others is often a precipitant for initiation of involuntary care, the process of assessment helps sharing of responsibility with caring services [13].

### **Needs and perceptions of families and carers must be considered, but involuntary care decision must be informed by the needs of the person**

Information provided by the family assists with the process of any clinical assessment. However, it assists greatly in the process of assessment for involuntary care. Families can inform about the person's general ability to make decisions that are in their best interest, the extent to which the immediate crisis may have impacted on their ability to make autonomous decisions and how best to communicate with the person with intellectual disability. Families can also provide valuable information about the person's needs, desires and expectations and what they would prefer to be done to them [14].

However, irrespective of views, opinion and perceptions of family and carers any assessment to make involuntary care decisions must also be done with due consideration of important ethical considerations. Involuntary care does have significant impact on autonomy and freedom of the person. If the assessor chooses to give more importance to the patient's autonomy than immediate treatment needs and risk the person intellectual disability may present at that time, they would be doing a disservice to the person with intellectual disability. If the functioning of the person with intellectual disability deteriorates they can make inappropriate financial, other material or social decisions that would have an adverse impact on themselves, their family and even the wider community. On the other hand, if the assessor is defensive in his or her practice, overrides autonomy considerations when that is not really warranted, and uses the legal provisions inappropriately, that can leave long term consequences for the person. Sometimes compulsory treatment is dressed up as a medical decision to gain social control of a behavior that is seen to be slightly deviant by the family members, carers and the community in general [14].

Most assessors are able to justify and rationalise use of involuntary care provisions as a beneficent and non-maleficent act that is in the best interests of the person with intellectual disability and one that would enable the person to receive appropriate care and return to their autonomous self in due course. However, the need to mandate involuntary care can also present with a potential role conflict for assessors and other clinicians. Many experience this dilemma in carrying out their legislated responsibility that requires them to overrule wishes of the person they are supporting as well as their own clinical orientation to facilitate recovery, empower people with intellectual disability to make decisions and enable them to be more autonomous. This can place assessors in a double bind - being simultaneously accountable to the person for care provided as well as to the social and legislated requirements, with varying objectives and focal points.

## Conclusion

The process of involuntary care of a person with intellectual disability is a legal process to safeguard the person concerned. Even though the primary purpose and objective of involuntary care may be remedial and therapeutic, it is also there to protect the community.

A decision about involuntary care has to be informed by a number of considerations. These include input of the families who would have previously, and will in future, provide support, care and treatment to the person with intellectual disability. Families and carers involved in supporting the person with intellectual disability are able to provide longitudinal objective evidence of the person's intellectual ability and capacity at the point of assessment.

The process of assessment for need for involuntary care does present many complexities for families and caregivers. While the family's or caregiver's request for assessment to access involuntary care is to protect the person from perceived risks [to themselves or to others] and to prevent negative consequences of their intellectual disability, compulsory assessment and treatment does result in limiting the liberty of the person. Family members concerned about the deteriorating mental state and ability to function of the unwell member of the family are often the one who request assessment. This process has the potential to put them in conflict with the person who may not necessarily perceive the need for assessment and treatment and, in many instances, may be opposed to it. In an effort to act in the person's best interests, at times, family members find themselves in direct contradiction of the desires of the person. Many accuse them of colluding with assessors and support services to get them admitted under compulsion.

It is important that the assessment of the need for involuntary care considered views, opinions and perceptions of the family, but the assessor must make decision in relation to involuntary care with the best interests of the person with intellectual disability while protecting the family and cares from the conflict that the

process of requesting involuntary care may present for them.

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