Informed Consent

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Values governing the need for informed consent 'promote and protect a person's well-being' and 'respect a person's self-determination' (Buchanan & Brock, 1990). Realising these values has proven to be problematic for people with intellectual disabilities, and those who support them, and as such, are a central focus of this chapter. While a vital component of supporting people with intellectual disabilities to make informed choices in their living, evidence suggests that informed consent means different things in different contexts and settings, variably practiced and rarely achieving the theoretical ideal. This chapter sheds light on and contributes to the theoretical and practical discourses of seeking, obtaining and facilitating informed consent for persons living with intellectual disability. Guided by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) reasoning on 'rights' and 'disability' this chapter relates the notion of informed consent and activities of consenting with particular relevance to the application of CRPD's Article 12 (Arnardóttir & Quinn, 2009; Werner et al., 2012).

The chapter firstly traces the history of consent theory from pre-modernist, modernist and post-modernist perspectives. The evolving nature of informed consent is addressed and changing perspectives described noting the significance of evolving concepts of autonomy and self-determination specifically as relating to intellectual disability. Firstly historical reflections signify how deprivation and infringement of rights occurred (Kayess & French, 2008; Stein, 2007) often due to the absence of safeguards to insure that consent was informed rather than being coerced (Iacono & Carling-Jenkins, 2012). Secondly, aligned with the rise of bioethics, the endorsement of autonomy and self-determination of intellectually disabled individuals is demonstrated which aims to challenge readers to think of informed consent as more than personal rights but as augmenting inclusion in society. Thirdly, supported by two figures (Figs. 14.2 and 14.3) the principal processes and interactions of informed consent are presented which recognise both the simplicity and the multifactorial nature of informed consent communications, which require active involvement of those involved. Ultimately, this chapter demonstrates the enablement of intellectually disabled people to provide informed consent in all matters related to their life choices, and especially so for such examples as, receipt or use of a service, an intervention, or participation in research.

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Historical Developments of Consent

Despite the fact that numerous people from theology, law, anthropology, philosophy, medicine, nursing, psychology, sociology and psychiatry have debated the political, legal, ethical and moral issues and processes of consent, compared to many other areas in scientific enquiry, consent continues to be an evasive concept as no unifying theory exists. An overarching view of informed consent has been restricted. It is a widespread and varied phenomenon and despite extensive research and debate, remains deeply puzzling. In a capsulated review of consent theory, the literature abounds with studies representing theoretical perspectives that have influenced the study of informed consent, shaping and reshaping societies' understandings.

It is beyond the scope of this chapter to explore every theory or every writer; therefore, it is limited to works and writers taken as indicative of a particular era, and have influenced Western and Christian cultures. Three epochs of pre-modernism, modernism and post-modernism are utilised to provide a framework to debate the various discourses of consent. These three epochs produce three very different ways of understanding consent. More importantly, as the rise of consent theory has been diffuse, haphazard and a very slow process, it would be absurd to champion specific dates. To some extent these epochs overlap and it is the dominant philosophical system of the time and associated belief system as opposed to chronological time that is emphasised. The discourses presented highlight the different perspectives that prevailed and the manner in which permissions, prohibitions and alliances have been constructed based on each discourse. Table 14.1 provides an overarching framework, which has been conceptualised to guide some of the discussion in this chapter. Discussion of the various discourses lends insights into modern-day consent modes held by cultural institutions medicine, nursing and research.

Table 14.1 An overview of the discourses on consent

Pre-modernist discourses	Modernist discourses	Post-modernist discourses
A source of harmony	A source of liberalism	A legal-political concept
A source of conformity	A source of obligation	An ethical-legal concept
Control vs. autonomy	A question of morals	A basic human right
	An acknowledgement of rights	A communicative interaction

Pre-modernist

The pre-modern epoch extends from approximately the beginnings of western civilisation, in ancient Greece, through to the beginning of modernity in the early fifteenth century. The primary epistemology of pre-modernism emphasised the use of mythical thinking and myths to explain and interpret the world by the first civilisations of ancient Mesopotamia and Egypt. In exploring pre-modern discourses, including reference to consent in ancient Greece and consent codes of practice described by theologians with the Christian church, an enabling understanding of consent is conceptualised as 'a source of harmony' and 'a source of conformity' identifying informed consent as an ethic of subjection to religious authority and social order.

In this era, many writers spoke in terms of hierarchy and consensus, unity and subordination where social order required one unified hierarchy, with such matters involving counselling of the rulers and consent by the ruled (Herzog, 1989). Early pre-modern history therefore offers a concept of 'tacit consent', which is not necessarily verbalised, explicit or formalised. Regarded as implicit, 'tacit consent' denotes the tranquil and serene adhesion of the community to any determination presented as such, to a specific form of action, which was perfectly integrated within the customs and habits of that community and thus legitimated by norms and tradition' (Nerves 2004). The state of things was generally seen as unchanging, and the social order was strictly enforced. Consent evoked a common sense of feeling confirmed by habit or tradition rather than being understood as an individual prerogative, nor as the expression of the exercise of any (Fletcher 1983). Influenced by an enmeshment of religious and political activity, cultural and societal habit and tradition dominated routine choice. In other words, 'consent' referred to what was in conformity (what agrees) with the customs and habits of that community without being requested or granted explicitly or formally (Fletcher 1983). Such practices greatly reduced opportunities for understanding individual will and preference.

It was the Greeks who instigated ideas of political freedom, whereby thinkers, such as Plato and Aristotle developed ideas of statehood noting attributes such as the ability to reason and to exercise intelligence as being distinctively human. At the beginning of the tenth century, as the Church began expanding and secular kingdoms arose in supremacy, both church and kingdom struggled with issues of power over ultimate authority. The end of this era depicted the emergence of *rivals* to consent such as freedom and liberalism which still dominate consent discussions to the present day.

Modernist

The Modern era extends from approximately the early fifteenth century to the middle of the twentieth century. Modernism is known as the Age of Enlightenment, which emphasised a belief in human progress through rationality and the methods of science (Rolfe, 2006). The Age of Faith gave way to the Age of Reason. Discourses within this era focused efforts to rationalise behaviour on a scientific footing. Enmeshed in the generation of scientific knowledge and understanding and of new perspectives consent theory developed. Such perspectives began a change in focus from mythical beliefs, religious supremacy and moral constraints to concepts of liberty, freedom, obligations, morals and eventually rights.

The major theorists in this era Locke, Kant and Montesquieu presented discourses of consent which implied normative assumptions in that individuals behave according to the norms of the societies in which they live. In contrast to the pre-modernist control and conformity thinking around consent this paradigm shift marked the cornerstone of modern liberalism viewing society as a collection of free individuals (Herzog, 1989). Early modern theorists clearly supposed that individuals had basic normative powers over themselves before they entered into social contracts, which brought questions of political obligation to the fore. In the early stages of this era the main thrust of discourses surrounding consent focused on liberalism and obligation versus issues of morality and rights. Arguing that individuals were rational and freethinkers challenged previous mythical beliefs, religious supremacy and moral limitations. But due to nature that such individuals were living in societies which were governed by religious and political authority which determined social order these discourses of the modernist era became entangled in controversy. The main debate being that when individuals have the power to bind themselves by exercising the normative power, then the upshot of the social contract becomes obligation.

Kant challenged Locke's theory of natural law and natural rights emphasising morality as a general term for an individuals or a society's standards of conduct, both actual and ideal, and of the character traits that determine whether people are considered 'good' or 'bad' (Levine, 2008). In its simplest formulation, an act that is moral brings more good consequences than bad ones. This gave rise to a consideration of how morals and ethics impact consent. Kant believed that because of the constitution of the mind of an individual, they presuppose a relationship of cause and effect in all experiences with the objects of this world.

Kant (1795) claimed that consent was not fundamental to a social contract view but rather that the inner voice of individuals, the conscience, was the source of morality, which informed individuals of what was right and commanded them to do their duty. Often called deontological, this approach has been increasingly called Kantian, because of its origins in the theory of Immanuel Kant (1724–1804) (Beauchamp, Walters, Kahn, & Mastroianni, 2008).

The conceptualisation of consent in this era introduced notions of rights and the role consent plays in determining and enacting the legitimate ends that governments can pursue. Since Governments existed by the consent of the people in order to protect the rights of the people and promote the public good, governments that failed to do so could be resisted and replaced with new governments. Montesquieu (1689–1755) alleged the study of political and social behaviour not to be an exercise in abstract thought, but rather to be undertaken in relationship to geographic, economic, and historic conditions. Montesquieu claimed that such conditions, along with customs, habits, religions and institutions, gave each nation a particular character, and therefore each society required constitutional forms and laws that reflected and supported the character of its inhabitants. The consequences reflected in this paradigm shift in the change of thinking about liberalism as individual rights taking precedent over collective rights has major implications for adults with intellectual disabilities (discussed in section-rise of bioethics). Modern theorists' contribution to consent theory primarily insisted consent be deliberate, voluntary arising from self, all-be-it either individual or group consent.

Post-modernist

In the context of consent, post-modern theorists challenged previous discursive constructions of consent and questioned the taken for granted assumptions that were used as a basis for knowledge construction. Post-modernism adopted a critical approach to all knowledge, highlighting the inter-relationship between truth, knowledge and power (Kaye, 2007). Post-modernists rejected many of the principles of the scientific revolution arguing that society is characterised by differences as opposed to commonalities. Rather than trying to find a common theory or narrative to guide all actions, post-modernist theorists developed and consolidated consent by integrating it within a coherent and unitary system, which acknowledged historical and social contributions while integrating legal, political, moral and ethical principles grounded in appropriate communicative transactions.

Post-modernists argued consent to be a complex process founded in historical and cultural social constructions. The focus of these theorists was on deconstructing concepts that had been used to construct consent theory and to develop new approaches to informed consent. The outset of the post-modernist era coined the term 'informed consent' as a legislative concept that marked the beginning of an explosion of discourses and the production of a variety of modes of informed consent, which became instruments in the surveillance, regulation and control in maintaining human rights. Major theorists exploring consent in the initial part of this era were Ramsey (1930), Jonas (1969), Veatch (1972) and Fletcher (1978). Further developments are reflected in seminal works of Beauchamp and Childress (1979), Fadan and Beauchamp (1986), Beauchamp and Childress (2001), Berg, Appelbaum, Lidz, and Parker (2001) and Manson and O'Neill (2007). Informed consent began to be viewed as an ongoing process, a safeguard of personal statute, with communicative interaction as being recognised as one of the most critical elements involved.

The key contribution of the post-modernists era is the manner in which legal, political and ethical standards focused on respect for individual autonomy and inalienable rights. In other words, 'informed consent' theory was borne out of respect for individual autonomy, paralleled with the rise of the bioethical movement and debates around issues of gaining consent particularly relevant to minority groups such as people with intellectual disabilities. This focus served to promote a person's right to self-determination, often happening within the context of the need for safeguards and complex communicative transactions within the decision-making process. Some of these pertinent issues are highlighted in the following sections.

Rise of Bioethics and Informed Consent

Noting historical developments of informed consent, it is clear to see how the expansion of informed consent practices and regulations have occurred in tandem with the broader evolution of society, noting bioethics and ethical participation of human subjects in research as significant movements in which the discourse of informed consent has given rise to contentious debate. Bioethics is integral to these considerations because it examines the ethical, legal and social issues of advances in bioscience in a number of disciplinary domains, namely ageing and end of life, clinical ethics, life sciences, disparities in health and healthcare and disability.

A notable abuse of humanity reflected in modernist times refers to the eugenics era, a movement purporting to 'improve the genetic composition of the human race'. Given the extent of the subject area, the brief outline of it here is inevitably illustrative rather than comprehensive. Basically, between the years of 1907 onto 1957 the eugenics campaign sought to promote a genetic purity which was guided by a White supremacist colonial project designed to maintain the purity, superiority, and health of the default, that being the White race (Llyes, 2018). Psychological and intellectual assessments played an essential and powerful player in this eugenic project (Winston, 1998) with new ways of classifying people, through a brief consideration of an essential psychological concept, 'the normal distribution', culminating in a statistical visual organising tool for populations (Hacking, 1995). And in rounding up the very tail of the normal distribution of population level intelligence quotient (IQ) scores, psychologists classified many people as feebleminded, imbeciles, idiots, and institutionalised. And for those who fell within this remit, many were subjected to atrocities such as forced sterilisations and inhumane institutionalisations.

Forced Sterilisations (Early 1900s)

Advancing this ideology of the eugenics perspective, societies' obligation was to prevent those considered 'feebleminded' from procreating so as to prevent 'them' from 'continuing their kind'. In the early 1900s the United States of America was the first country to undertake sterilisation for eugenic purposes, unleashing a global wave of forced sterilisations across many countries including Canada, Australia, Germany, Belgium, Scandinavia, Japan, China, India, Taiwan and South Africa. And by 1963 over 60,000 people in the USA had been sterilised without their consent (Roy, Roy, & Roy, 2012). However, Universal Human Rights have subsequently driven agendas to uphold the rights of people, by proclaiming that the necessity for each individual to provide informed consent on such decisions. More recently in 2014, in conjunction with a number of organisations the World Health Organization issued a joint statement: 'Eliminating forced, coercive and otherwise involuntary sterilization, An interagency statement' (WHO, 2014) which references the involuntary sterilisation of a number of specific population groups including women with intellectual disabilities.

The Vipeholm Sugar Trial (Sweden 1947–1955)

At the beginning of the twentieth century, Vipeholm, in Lund Sweden, was the only state hospital which catered for the needs of approximately 800 individuals who were intellectually disabled, classified at that time as the 'uneducable mentally deficient'. During this time, 'tooth decay' had become increasingly prevalent in the Swedish population. In order to establish an effective preventative public health strategy, the government commissioned the Folktandvåren (Public Dental Service) and Medical Board to establish an interdisciplinary team at Vipeholm to identify the cause of dental caries.

In 1947 progressing the Vipeholm Dental Caries Study, adding sugar to the basic (standard) diet of 436 patients in various controlled formats over the course of each day resulted in 2125 new dental caries been induced by the end of the study in 1953. Findings from this study have advanced our understanding related to oral health, and considered the most significant contributions to the entire dental literature as it:

> '*…definitively established that the more frequently sugar is consumed, the greater the risk, and that sugar consumed between meals has a much greater caries potential than when consumed during a meal'* (Zero, 2004)

However, ethical issues were not discussed formally either before or during the study and none of the patients involved in the study had given their informed consent (Zero, 2004). Subsequently, legislation was introduced which prevented the use of Vipeholm patients as research subjects (Zero, 2004). Similar inhumane treatment of children with intellectual disabilities was evidenced in the Willowbrook studies.

The Willowbrook Study (United States of America 1963–1966)

In the United States of America, the Willowbrook Study reflects a significant case of advance in medicine (Krugman, 1986). In this period of 1963–1966 over 700 children at the 'Willowbrook State School' were involved in a 'successful' experiment that discovered a vaccination for hepatitis under the principal investigator Dr. Saul Krugman. Krugman states that parents were informed that their children were likely to have only a sub-clinical infection followed by immunity to the particular hepatitis virus, and only children with parents who gave informed consent were included. The research subjects were all children deliberately infected with the hepatitis virus. Critics of this research differ in opinion, related to unethical or questionably ethical procedures involving risks to the health and consent which portrayed cognitive privileges in dehumanising individuals with intellectual disabilities (Carlson, 2009) and questions related to the concept of 'informed consent' (Iacono & Carling-Jenkins, 2012).

Children's diets consisted of extracts of stools from infected individuals, while others were administered injections of more purified virus preparations. For example, coercion and pressure have been identified as concerns for parents of children with intellectual disabilities, a notable case in the early 1970s, the 'Willowbrook State School for Children with Mental Retardation' (Klotz, 2004, Carlson, 2009, Iacono & Carling-Jenkins, 2012).

However, if consent obtained through coercion or parents feared losing their children's placements in the school, the principle of voluntariness of consent had been violated. Moreover, due to crowding and long wait lists for admission to the school, minimal home supports, and available rooms for children on the experimental wing, thus influencing the decision of some parents who did not have the resources to care for their children (Iacono & Carling-Jenkins, 2012). Krugman re-visits the ethics of this research in his 1986 paper recognising '*the accomplishments of the research to be well documented in the medical literature*' arguing that the development of a vaccine would outweigh the anticipated 'minor harms' to these children (Krugman, 1986). It is clear to see how the polarisation of risks and benefits of informed consent gives rise to many debates and controversial considerations in health services and research.

Ethical Considerations for Human Experimentation and Research

In efforts to protect the rights of people from abuse, the first international code of ethics, The Nuremberg Code, was established in 1949. The central declaration of The Nuremberg Code (1949) was that the voluntary consent of every human subject would be obtained prior to research being undertaken (Beauchamp et al., 2008). In 1964 The Declaration of Helsinki advocated prior review of research protocols by an '*independent committee*', as well as making explicit provision for participation in research by legally incompetent persons. Early history of research ethics policy focused on the risks and on preventing subjects from being exposed to unacceptable or exploitive levels of risk (Fadan & Beauchamp, 1986).

The Belmont Report (1978) later outlined what was considered the three most important ethical principles (respect for persons, beneficence, and justice) that should govern the conduct of research with human beings. And the 1994 National Institute of Health (NIH, 1994) guidelines ensured that research inclusion gained momentum over research exclusion. Therefore, the presumption about research participation flipped from exclusion (protection from risk) to inclusion (enabling autonomous choice about participation).

More recently, legal and international human rights framework emphasise the capacity of the intellectually disabled for social, physical, emotional and intellectual development, and in doing so, concepts of autonomy and independence have become central features (UNCRPD, 2006). Furthermore, in Article 31 of The United Nations Convention on the Rights of Persons with Disabilities (2006) researchers are now required to include representative populations of minority groups unless there are special reasons for excluding them. Published ethical guidelines for conducting research with people with Intellectual Disabilities has now come to the fore Lai et al. (2006). While various philosophies in relation to research ethics are now widely debated, Biggs (2010) accepts that no single theory or principle can be adopted as a guiding philosophy for researchers or research ethics committees (RECs). Biggs proclaims that REC decision-making needs to balance various approaches to arrive at a consensus decision. Conversely, McDonald et al. (2009) have argued that blanket prohibitions imposed by Institutional Research Boards may actually limit the autonomy and self-determination of intellectually disabled individuals and thereby increase their marginalisation in society.

Evolving Definitions of Informed Consent

The concept of informed consent has been described as evolving over centuries by different schools of thought. The changing definitions of informed consent have reflected changing attitudes to how best to seek, obtain, and maintain consent when engaging people, especially those regarded as being vulnerable. Generally legal, political, moral, regulatory, philosophical, medical, and psychological literature favour components of informed consent to include: (1) disclosure; (2) understanding (3) voluntariness; (4) competence and (5) consent. For example, Appelbaum (2007) conceptualised consent as encompassing four components, which include the ability to: (1) understand relevant information; (2) appreciate the consequences of the information for one’s own situation; (3) reason about the available options; and (4) communicate a choice. And specifically with regard to people with intellectual disabilities, Dye, Hare, and Hendy (2007) identified three main components of informed consent as: (1) possessing sufficient information relevant to the decision to be made; (2) having the capacity to make a decision and to understand the consequences of the decision; and (3) making the decision voluntarily and free from coercion. While focus shifted to consent capacity as being the determining issue in obtaining informed consent, defining it as ‘ability to understand information relevant to making an informed, voluntary decision’ (National Institutes of Health (NIH), 2009), the need to regard informed consent as a ‘respectful relationship’, and as a ‘process’ rather than a one-off event placed more onus on advocates for facilitating resources to enhance informed consent experiences, especially for those with intellectual disabilities (DHSSPS, 2003). And more recently, the boundaries of what exactly constitutes ‘informed consent’ have been broadened by specifically constructing the concept from an ethics of care perspective, created in notions of relational autonomy-in-informed consent (RIAC), which when placed within the remit of care ethics attracts global perspectives so as to enrich current ideas of bioethics principles of autonomy and informed consent (Osuji, 2018). Figure 14.1 presents a Venn diagram showing the multiple overlapping purposes of informed consent (Hall, Prochazka, & Fink, 2012).

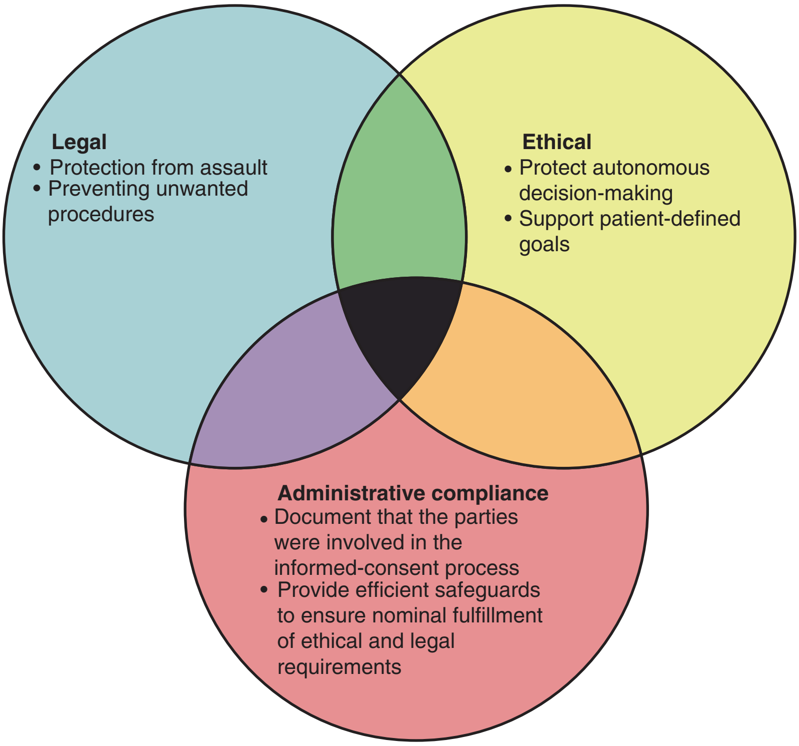

Fig. 14.1 Purposes of informed consent

Informed Consent Approaches

In asserting post-modernist theorists views of consent the following paragraphs and figures explicate the authors understanding of how informed consent can foster the autonomy and freedom of intellectually disabled people to make an informed decision. Infusing values of self-determination and choice can be challenging when people experience complex communication needs, impaired social interaction and limited experience of choice in addition to difficulty making informed choices for themselves (Bigby, Fyffe, & Ozanne, 2007), but not impossible. The following approaches Fig. 14.2: 'Gaining Informed Consent: A Process', and Fig. 14.3: 'Informed Consent Gaining: An Interactive Cycle' illustrate this perspective.

Gaining Informed Consent: A Process

The following Fig. 14.2 presents the standard 'Gaining Informed Consent: A Process', which portrays disclosure; understanding; voluntariness; competence and consent.

This framework has evolved from the initial focus whereby consent conveyed by an individual has been sought and obtained in culturally and linguistically appropriate language. Additionally, where written agreement has been utilised, integral in the act of signing and the existence of the signature is the credibility of the above-mentioned components of informed consent. Generally, the onus of proof of capacity has not been on the person seeking consent but rather on the consenting individual. In this standardised approach to gaining informed consent; the assimilation of and processing of information; the

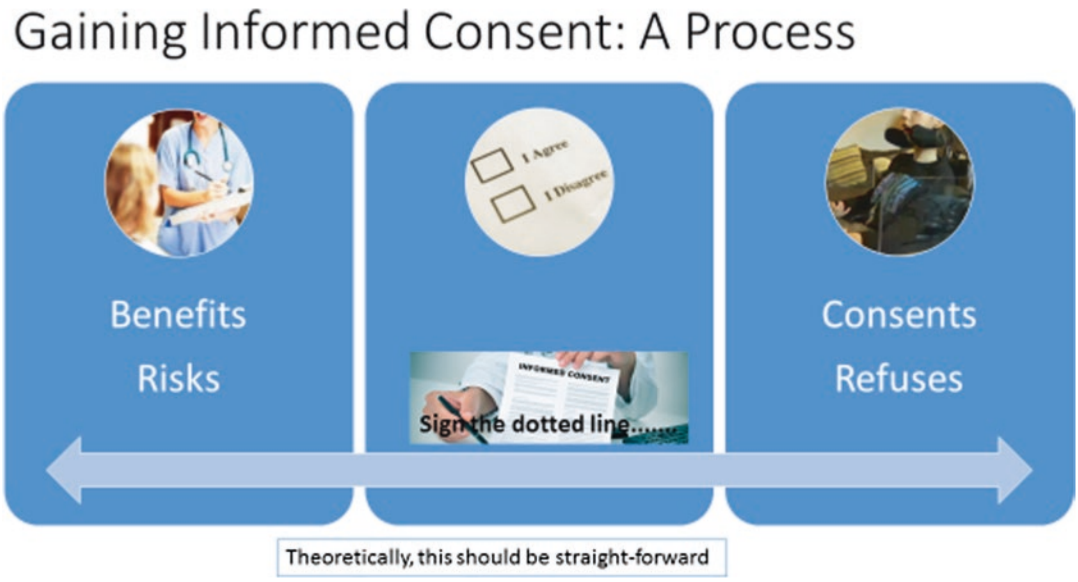

Fig. 14.2 Gaining informed consent: a process

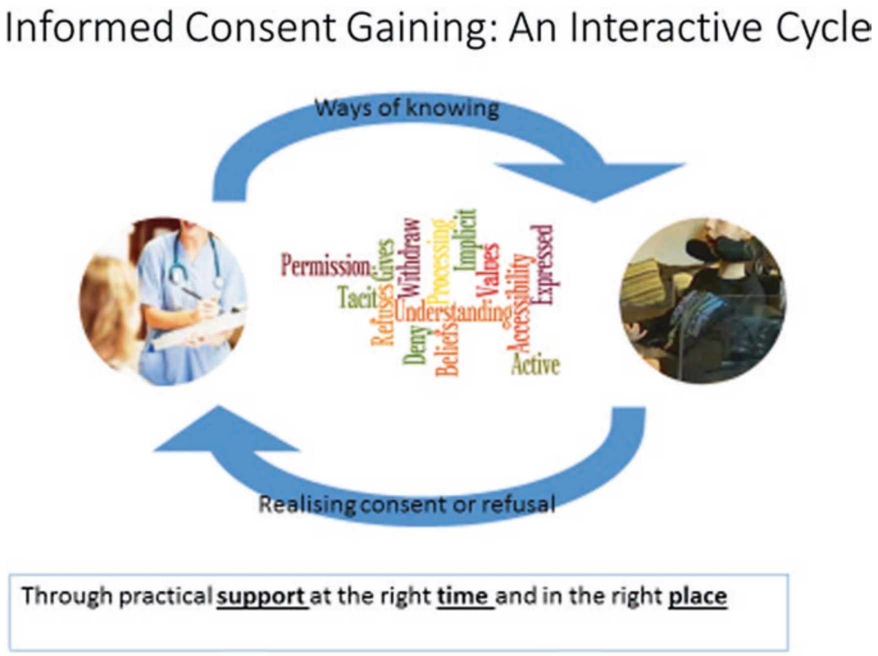

Fig. 14.3 Informed consent gaining: an interactive cycle

making of a judgement and the communication of a voluntary decision demonstrates the embodiment of theories of cognition and rational decision-making. Cautionary notes indicate such emphasis has rendered many people with disabilities, especially those with intellectual disabilities, disadvantaged in terms of communicating and explaining personal choices in these cognitive and rational domains. Particularly for those with moderate, severe and profound intellectual disability, the process of informed consent has traditionally been guided mainly by a status approach,[1] which determined that these individuals, by the nature of having an intellectual disability, did not have (legal) capacity. These people, subsequent to being deemed to lack capacity, were subjected to the enactment of guardianship laws. Reflective of individual and society responses to protecting those regarded as being vulnerable the introduction of guardianship laws aimed to demonstrate responsibility towards people at different periods in their lives, placing many people within custodial remits. And when rolled out in practical situations for people with intellectual disability, guardianship laws by the very nature of excluding them from matters of disclosure, voluntariness and choice rendered many unable to engage in the process of informed consent. Opportunities to make or engage in life choices was severely restricted for those who found themselves segregated by custodial care provisions. There is little doubt that the status approach obliterated the human rights of many people to engage and participate not only in having choices and making decisions for themselves as individuals but also in contributing to group and wider society decisions, erroneous thoughts in light of newer understandings of how this minority group of people can participate in making life choices.

Informed Consent Gaining: An Interactive Cycle

The 'interactional' perspective in Fig. 14.3 asserts the importance in developing meaningful relational interactions in time and over time to enhance mechanisms to develop engagement in disclosure (alternative and augmentative communication strategies); understanding (trust and relational); voluntariness (checking for signs of assent and dissent; comfort zones); competence (at ease to make a decision-with required supports) and consent (acceptance or refusal).

By gaining informed consent from people with intellectual disabilities, a 'respectful relationship', rather than a one-off event, is advocated enhancing interactions over a period of time. The impetus for this challenge reflects the beliefs in maximising human potential and services required to meet individual needs and outcomes while avoiding emphasis on limitations to understanding disability.

Underpinning these beliefs the value of communication displayed in 'Informed Consent Gaining—An Interactive Cycle' aims to present how meaningful and trustful relationships inherent within informed consent, placing emphasis on human potential, guided by a supports based approach. This philosophy aligns with the assumptions and understandings of the UNCRPD (2006) Handbook for Parliamentarians on the Convention which describes support in decision-making as:

> '*Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realise that a person with significant disabilities is also a person with a history, interest and aims in life, and is someone capable of exercising his/her legal capacity*' pp.X

This interactive cyclical nature of seeking, obtaining, maintaining consent and/or respecting refusals or withdrawals to consent is underpinned by two principles, (a) *ways of knowing* people and (b) *maximising human potential*.

Ways of Knowing

A fundamental aspect of consent gaining interactions is that it challenges the '*ways of knowing*' people, from a pathological model where persons were perceived as objects or 'labels' in contrast to people with the potential to flourish as masters of their own lives, ability to self-determine, with a life plan and pathway, a life story or narrative (Bach & Kerzner, 2010; Barnes & Mercer, 2010; Department of Health, 2009; HSE, 2011; Lashewicz, Mitchell, Salami, & Samantha, 2014). In illuminating '*ways of knowing*' the practical implementation of supports, needs to take cognisance of individual values and principles that recognise contributions within communities.

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[1] Status approach determining that capacity related to intellectual functioning and IQ singularly

With the right support, people with intellectual disabilities can exercise their right to make decisions and consent to life choices of their choosing. Willingness of support persons not only to listen to the person but to hear what the person is inferring via signs and expressions, recognising their individual and often unique mechanisms of communication. This lies at the heart of knowing the person. For this to be achieved personal supporters, support networks and/or circles of support should understand a person's life history, individual needs, routines, preferences and forms of communication. The value of familiarity and trust within any support for people with intellectual disabilities must be acknowledged since it evolves around supporters' willingness to develop connections, establish and sustain meaningful interactions (de Haas & Ryan, 2016).

Maximising Human Potential

The second principle of consent gaining interactions is that it must no longer consider intellectual disability as an absolute invariant trait of the person. Disability as a concept is viewed as a social–ecological construct exemplifying the interaction between the person and his or her environment. Therefore communications must focus on the role that meaningful interactions play in enhancing human functioning, self-worth and subjective well-being, so '*maximising human potential*'. Therefore when making a presumption that every person has the right to make decisions and be supported to exercise these rights (ACT, 2015; MCA, 2005), a movement beyond rational and cognitive theories therefore underpins the informed consent process, requiring recognition of affective theories (Cifor, 2016), which minimises the risk of 'absorbing the other'.

Expressing the changing understanding that intellectual disability needs to be recognised beyond an inherent pathological disorder to a more inclusive social ecological functioning, aids in reforming not only systems of support that people living with intellectual disabilities require but also the paradigm shift in medical, legal and familial understandings of delivering the practical functional supports required. In light of decisions to be made, taking cognisance of the timing of these decisions, people with intellectual disability should be supported to provide informed consent via a functional approach to decision-making in order to successfully engage in either or both of the above mentioned approaches.

Being Active Agents within Informed Consent

The following paragraphs demonstrate how people with intellectual disabilities can be supported to be active agents central to decision-making when providing informed consent. The aim being to diminish notions that people with intellectual disabilities are non-progressive and hold perpetually undeveloped cognitive capacities. Maximising decision-making capacity, supported decision-making models and circles of support demonstrate how people can be supported to be active agents within informed consent.

Maximising Decision-Making Capacity

It is now widely recognised that many individuals with intellectual disabilities are capable of providing informed consent with minimal, if any support. For others consent processes need to be tailored to maximise decision-making capabilities. Meaningful interactions need to be incorporated in order to provide support to individuals at the time the decision is to be made, taking cognisance of disclosure (of the procedure, expectations, benefits, risks); understanding (interpretation of information); voluntariness (having a choice, autonomy, self-determination, lack of coercion); competence (ability to make a decision-with required supports) and consent (acceptance or refusal).

For a person to be able to exercise decision-making capacity and make informed decisions, supported in a social and political environment, which recognises and promotes the value of autonomy allowing it to flourish is required (Atkinson, 2007). The terms autonomy and self-determination are sometimes used interchangeably but distinguishing between the two is helpful in relation to understanding 'informed consent'. Atkinson (2007) describes the difference between these terms as follows:

> *Autonomy is the capacity for self-government and self-determination: the ability to choose for oneself. (…/…) Self-determination requires an individual to have the capacity to formulate and carry out plans, desires and policies of their own devising. Self-government further requires the individual to take account of their own rules and values in making these choices* (Atkinson, 2007)

In maximising decision-making capacity, a recognition of the inherent values and respect for humanity in promoting autonomy and self-determination of all people, post-modernists move beyond the status approach of whether a person has capacity or does not have capacity, to acknowledging the wide range of applicability attributable to the moving statuses and functional approaches[2] to maximising capacity. The ability to understand the nature and consequences of a decision, when communicated in appropriate and respectful means, in the context of available choices, at the time the decision is to be made, with supports and accommodation ensures that a person is in a position to exercise their legal capacity.

As post-modernist perspectives of consent are adopted, and the philosophy and understanding of the United Nations Convention on the Rights of People with Disabilities the following definition of legal capacity supporting informed consent is fitting:

> *'Legal capacity to me is a continuum that connects with everything needed to enable the person to flourish—a right to make decisions and have them respected, a place to one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings. Personhood is broader than just capacity—and these broader connections serve to augment capacity in a virtuous circle'* (Quinn, 2011)

Therefore, this perspective flips the traditional belief that disabled people lack capacity to a belief in the unique ability of each person to express capacity by the nature of being a person. These changing beliefs represent a move in social processes from intellectually disabled people perceived as not having abilities, to favouring moving statuses and functional perspectives to viewing capacity as developing decision-making capability to self-determinate.

Supported Decision-Making Models

Supported decision-making models are now recognised as enablers to the implementation of practices facilitating people, especially those with intellectual disabilities, to provide informed consent when making life choices. The following addresses two prominent models of supported decision-making (SDM). Two models describing SDM, 'Maximising Decision-Making Abilities' (Bach & Kerzner, 2010) and 'Enabling Conditions' (Flynn & Arstein-Kerslake, 2014a), are conducive to the implementation of informed consent practices. From a Canadian perspective Bach and Kerzner (2010) conceptualise SDM as a process with outcomes, viewing SDM as:

> *'occurring when an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behaviour to determine his or her preferences through three different decision-making statuses'* (Bach & Kerzner, 2010)

The three statuses, (1) legally independent status, (2) supported decision-making status, and (3) facilitated decision-making status, are now presented.

Figure 14.4 demonstrates how providing meaningful supports and accommodations sufficient to the disabled person's unique needs and anticipated outcomes, over time, assists the disabled person in maximising their decision-making capability to exercise their legal capacity. This supports and accommodations approach significantly contrasts with the custodial nature of pervious historical approaches. Within this framework Bach and Kerzner identify decision-

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[2] Functional approach

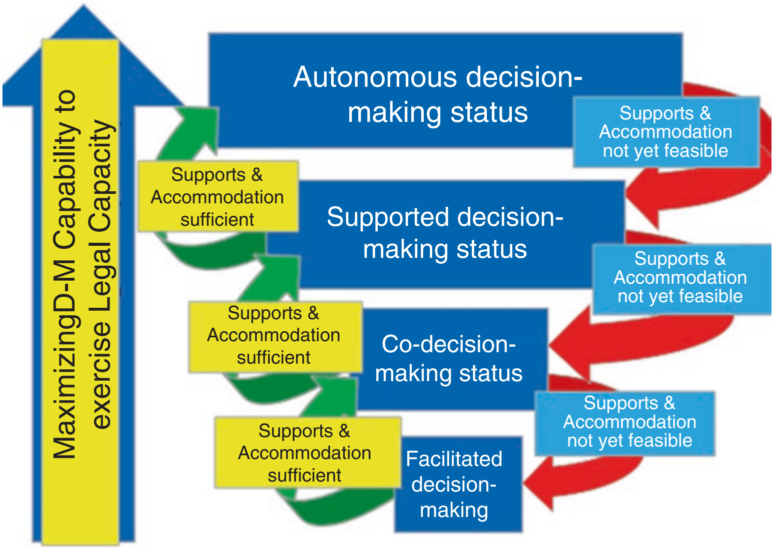

Fig. 14.4 'Maximising decision-making capacity' Bach and Kerzner (2010). This approach to 'decision-making capacity' advocated by Bach and Kerzner (2010) focuses on what accommodations and supports a person requires to manage the decision-making process in a way that maximises their decision-making capacity and thus exercise legal capacity

making statuses, which aim to be consistent with the person's identity. In general, while conceptualising distinct 'statuses' they acknowledge movement between legally independent and supported can be made, depending on the decision in question and the time the decision is made. The conceptualisation of SDM purported by Bach and Kerzner (2010) as a process with outcomes underpins decision-making capability has underpinnings in decision-making capability and seen as a relationship between decision-making abilities, decision-making supports and accommodations, and decision-making status. People move between statuses as abilities, supports and accommodations evolve reflected in Fig. 14.4.

The first autonomous decision-making status, familiar to most people, automatically recognises the person's capability to make decisions, by him/herself or with assistance, to understand and appreciate the relevant information, and the reasonably foreseeable consequences of, making a decision, therefore, exerting will and preference and exercising legal capacity. The first point on Bach and Kerzner continuum is the autonomous legal independent decision-making status, where an individual has the ability to make decisions on his/her own and is recognised as such. This may require reasonable accommodation to assist the decision-making process. One example of this would be ensuring that information relating to the decision is made available in a format which the person can understand (Goldbart & Caton, 2010), giving the person plenty of time to come to a decision, and enabling the use of informal support where the person can consult those closest to them in making the decision (The Office of the Public Advocate, 2014). This point reflects the ways in which most people make decisions by consulting others, while being free to accept or reject their advice.

In the supported decision-making status and co-decision-making status, a support person is appointed by the person with a disability, or by an administrative tribunal or court. This occurs specifically within a meaningful relationship between the person with a disability and his/her support person. The individual is provided with assistance in decision-making in any and all areas desired. This assistance can take the form of a circle of support, whereby the person chooses a number of trusted individuals to assist in the decision-making process (Atherton & Gates, 2007). These should be people who know the individual well, and can help interpret the person's will and preferences and communicate these intentions to third parties (Schalick, Westbrook, & Young, 2012), who are obliged to accept the decision as a valid one. The state should have a role in providing opportunities for support, enabling support

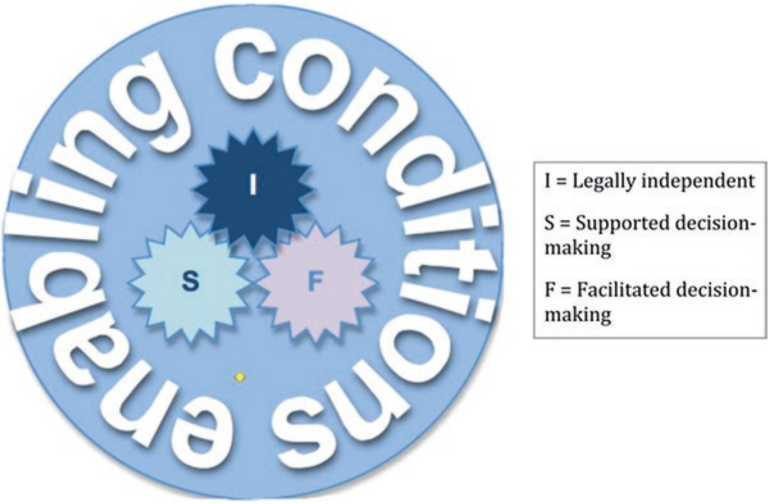

Fig. 14.5 Support model (Flynn & Arstein-Kerslake, 2014a). This model builds on the work of Bach and Kerzner (2010) and acknowledges the enabling conditions a person needs moving between the different statues of decision-making

agreements to be formalised and ensuring that decisions made through this mechanism are respected by third parties (Bach & Kerzner, 2010). Therefore, support person credibility to interpret the disabled person's will or intention, consistent with their personal identity becomes characteristic of supported decision-making, to exercise legal capacity.

In the final facilitated decision-making status a facilitator is appointed by administrative tribunal or advanced planning document (i.e., power of attorney). This decision-making status is applied as a last resort, where there is no circle of support or other person who could reasonably interpret the will and preferences of the individual. In this case, an appointed facilitator takes decisions on behalf of the individual, but does so with the will and preferences of the individual at the centre of the decision-making process and in the manner which best augments the person's autonomy and decision-making capability (Bach & Kerzner, 2010).

The benefits of Bach and Kerzner model is that is focuses understanding on the mechanism of SDM through 'decision-making capacity' when realising how accommodations and supports a person requires to manage the decision-making process in a way that maximises their decision-making capacity and thus exercise legal capacity, given their unique decision-making abilities. Building on the work of Bach and Kerzner (2010); Flynn and Arstein-Kerslake (2014c) purpose the 'Support Model' to SDM presented in Fig. 14.5.

Flynn and Arstein-Kerslake (2014a) SDM 'Support Model' image represents the overarching support model of legal capacity. The cogs in the centre of the circle represent the three statuses of decision-making: legally independent, supported and facilitated as previously outlined by Bach and Kerzner (2010). The major difference in the models relates to the area surrounding these statuses 'the enabling conditions' which include advocacy, reasonable accommodation, accessible information and communication, recognition of different forms of expression, advance planning tools, and so on.

The first principle of Flynn and Arstein-Kerslake model is that every person enjoys legal capacity regardless of his/her level of decision-making ability a principle of Article 12 UNCRPD, and each person should empowered to exercise his/her legal capacity through the expression of will and preference. Second, this requires the abolition of any assessment of decision-making ability (capacity assessment) which, if undertaken, may result in the loss of legal capacity. Any assessment which takes place in a support model of legal capacity should be centred on the support that is needed in decision-making to augment an individual's existing strengths, rather than the deficits of the individual (Flynn &

Arstein-Kerslake, 2014c). The facilitator's role is to imagine what the person's will and preferences might be and to make the decision on this basis. This distinguishes facilitated decision-making from substitute decision-making (Flynn & Arstein-Kerslake, 2014b).

Both models, Bach and Kerzner (2010) and Flynn and Arstein-Kerslake (2014a) are reflective of changing times, emphasising important aspects of the collaborative and relational aspects underpinning SDM in enabling a person to provide informed consent. The models require the abolition of substitute decision-making which subjects the will of an individual to the dominance of another's will or notion of what is in her 'best interest'. This does not prevent a representative from making a decision for another person who is not expressing her will and preferences in a way which anyone can interpret, rather, it requires representatives making such decisions to do so in a way which attempts to draw out the imagined will and preferences of the person (Flynn & Arstein-Kerslake, 2014c).

Recognising that many life choices can be complex, difficult to understand and challenging for some people, the following paragraphs introduce the concepts of circles of support providing for discussion of key elements required to support decision and enable a person provide informed consent.

Circles of Support

Popularity of circles of support in practice are emerging partly due to the philosophy and ideology surrounding the approach, perceived outcomes related to guidance (Macadam & Savitch, 2015), tangible resources and practical assistance (Lay & Kirk, 2011) and emotional support (Kaye-Beall, 2016). Circles of support originally designed to target social isolation and emotional loneliness have more recently been used as a support to intellectually disabled people to be autonomous in the decisions they make. Every circle is different because of the uniqueness of the individual at the centre of the circle and the uniqueness of the contribution of each circle member; therefore, it is important to recognise that one method will not suit all people who require support to make decisions, as everyone is different and will need different supports at different times (Browning et al., 2014).

Understanding person centeredness and circles of support contribute to understanding the ***ideology*** of SDM by facilitating individuals independence in decision-making, legal capacity and avoid having their right to control their decisions taken over by substitute decision-makers through co-production approaches. Perhaps worth noting however, even though a rights based approach to service provision is espoused, freedom and choices in identified service strategies to support this framework are currently more likely to revert support persons to charitable models and a dependency approach to support. For example, with family numbers reducing and family members more geographically dispersed, there is a need to look at natural support systems within local communities and this has been described as 'Circle of Friends' or 'Voluntary Workers' and 'Host Families'. These are generally unpaid and sustainability is challenging. These circles emulate principles similar to that of the social model of disability which recommends person-centred approaches of support to be achievable through assistance of local volunteers and often professional supporters, additional to paid workers (Lay & Kirk, 2011).

Circles have been given a variety of names and follow different models such as 'Self-Directed Support Corporations' and 'Circles of Support and Accountability' and are similar to methods of organising like 'Family Group Conferencing' (Neill & Sanderson, 2012). Therefore, the importance of basing care and support in addition to habitation practices and educational supports on substantial scientific evidence for practical, moral and legal reasons is acknowledged. Inclusion of evidence based practices contribute to the discussion of informed consent and intellectual disability. There is however a dearth of research and empirical literature in relation to circles of support notably in the areas of sustainability, productivity and cost effectiveness.

Trusting and Respectful Relationships in Gaining Informed Consent

Trusting and respectful relationships are pivotal constructs in the optimisation of autonomy pertaining to the life choices of people with intellectual disability. Yet consensus in the literature reveals that by the very nature of the label of intellectual disability, this population group are regarded as vulnerable (Parker, 2012; Parley, 2010) and subsequently their personal choices variably acknowledged and respected. The word 'vulnerable' is now widely used in health and social care, but its precise definition remains elusive, partly because of its universality and dynamism in that everyone becomes or feels vulnerable to a greater or lesser extent at different times in their lives (Pritchard, 2001; Rogers, 1997). Little, Paul, Jordens, and Sayers (2000): 495) identifies vulnerability as 'susceptibility to any kind of harm, whether physical, moral or spiritual, at the hands of an agent or agency' explicating the concept of vulnerability beyond the inherent disposition of an individual to (a) the role an external agent or agents, 9b) the notion of harm (either purposive or unintentional) and (c) the widening of the types of harm and safety beyond physical.

When vulnerability is recognised as being inherently human, perhaps a flaw with post-modernist conceptions of informed consent relate to the elevation of individualism at the expense of considering important relational and environmental considerations. This elevation of individualism minimises the interdependent nature of being and is perhaps not reflective of the experiences articulated by many intellectually disabled people. This chapter opened with the statement that values governing the need for informed consent 'promote and protect a person's well-being' and 'respect a person's self-determination' (Buchanan & Brock, 1990). Perspectives of both intellectually disabled people and those who support them should be established determining what exactly family, circles of support, citizenship, friendship and/or professional assistance looks like and how they work to ensure honesty, transparency and clarity when determining roles and functions. Therefore, the authors recognise how informed consent is based on the premises that all persons:

- Have decision-making abilities and make decisions.
- Require varying levels of support at different times.
- Receive appropriate communication to inform understanding.
- Experience trustful and respectful interactions.
- Have equal legal rights.

Building on the above premises, safeguards in post-modernist times especially for people with intellectual disability, provide that those who support this group of individuals are obliged to identify and act on the persons will and preference and to accept their determinations as valid decisions. It is the states' responsibility to ensure legal mechanisms are in place so as to explicate this will and preference. In the context of informed consent, the following sections present practical examples of access and participation in research and healthcare relevant to the lives of people with intellectual disabilities.

Informed Consent Gaining and Research Participation

As previously discussed, research was often undertaken about people with intellectual disabilities, rather than being inclusive of them, and often without their consent; therefore, such research participation was without safeguards (Taua, Neville, & Hepworth, 2014). Understandably, in the past number of years ethical regulation of health and social research has increased considerably (Wiles, 2013). Various international and national ethics guidance have now proliferated policies and procedures which enshrine the concept of 'informed consent' as the principal code to be adhered to protect the individual patient or healthy volunteer subject from possible exploitation and harm conceptually linking to discourses of human rights and autonomy. Particular challenges can present to researchers seeking to access population groups such as people with intellectual disability who are regarded to be some of the most vulnerable or marginalised in society, and researchers must ensure rigorous ethical safeguards are in place (Carey, 2010; Ramcharan, 2006). These people regarded to be vulnerable are entitled to participate in research while having their interests safeguarded (Smith, 2008).

Iacono (2006) describes the dilemma between the intentions of an ethical committee of protecting people with intellectual disabilities from potential harm when participating in research while guaranteeing them the autonomy to make their own decisions as they participate in research. Gilbert (2004) discusses the groups of people who may be involved and the influences they may have when research is undertaken in the field of intellectual disabilities. Diversity and complexity of lay and professional groups and individuals, along with knowledge, attitudes and power relationships are issues identified which can be influencing factors in research access and participation by people with intellectual disabilities. A prime example is provided by Carey and Griffiths (2017) who report that adults with intellectual disability were required to undergo physical and mental health assessments in order to be deemed to be fit to participate in a research study. These authors raised the question as to whether this was a reflection of principles of beneficence and non-maleficence or an act of discrimination?

Once ethical approval has been obtained potential participants with intellectual disability are often conscripted to research participation through intermediaries, such as their family, support workers, social workers, friends, unpaid carers or doctors (Nicholson et al., 2013). Formal gatekeepers are officially appointed within services whereas informal gatekeepers are people known to the person and who can influence the person's decision-making about research participation. For the duration of many research projects those who fulfil the role of formal gatekeeper are often managers nominated by organisations. Such gatekeepers are those people who control access to either participants or data (Gerrish & Lacey, 2007). Enlisting managers as gatekeepers can facilitate the research process and promote the best communication practices between the researcher, the participants and where necessary, families, about the nature and procedures associated with the research (Carey, 2010).

Conversely, undertaking such dual roles of gatekeeper and manager may also result in issues of power impacting the research, as gatekeepers have been regarded as people who can either help or hinder research depending upon their personal beliefs (McDonald & Kidney, 2012). Lee (1993) found that in some research, frequent attempts were made by gatekeepers to frustrate and circumscribe the studies, while in other research projects, gatekeepers had preconceived expectations of the appropriate methodology and refused access to the study population. Carey and Griffiths (2017) recommend to those proposing to recruit and undertake research with people with intellectual disabilities to consider:

- *The need to build and maintain trusting relationships with relevant formal and informal gatekeepers.*
- *To set time aside to understand the attitudes and concerns gatekeepers may have with regard to a research study, principally how it may impact on the potential participants with an intellectual disability, support persons and the service involved and to work to alleviate such concerns.*
- *To set time aside to get to know and understand potential research participants.*
- *To engage in reasonable accommodations to support decision-making with and for adults with intellectual disabilities so that they can make decisions about participating in research.*
- *Ensure the person understands what they need to do to participate, how the research actually applies to them.*
- *Endorse the activity of ongoing consent by ensuring the each participant is appropriately informed in a timely manner and where necessary offered reminders and repetitions of the processes involved while being vigilant and observant for signs of assent and dissent.*

- *Affording time for participants to process and assimilate information regarding the nature and procedures associated with the research study and their associated feelings and thoughts.*

Carey and Griffiths (2017) advocate the benefits of familiarity in enhancing research experiences for researchers, gatekeepers and people with intellectual disability. Familiarity of the ways of knowing the person can illuminate routine ways the person communicates, for example, how do they express how they want to opt in or opt out of ordinary life choices. By understanding the ways of knowing of the person the researcher can tailor the appropriateness of information sharing to the identified timely and decision-specific needs of the person. If researchers are to engage meaningful interactions with potential participants in order to identify their will and preferences and to gain informed consent then researchers need to spend time understanding their ways of knowing as expressed by these individuals themselves, an element which must be factored into ethics applications. Currently this is challenging as researchers have limited access to such groups prior to gaining their informed consent. Many researchers are not identifying frameworks which assist those undertaking research with people with intellectual disability who do not have time spent with the person prior to undertaking the research. For example, Taua et al. (2014) describes a qualitative research study undertaken in New Zealand. Taua et al. (2014) included individuals with a dual disability (intellectual disability and mental health issues). The overarching aims of the study were to understand what people with a dual disability and carers experienced during the time of an inpatient admission to a mental health service. University ethics approval granted in Australia and multi-region ethical approval granted by a national ethics committee in New Zealand. Making minor adaptations and additions to those originally developed by Dougall and Fiske (2008, pp. 73–75), Taua et al. (2014) presented a framework for researchers to follow during the consent gathering process taking cognisance of the following:

- *Communicate slowly and clearly, quiet location with minimal interruptions.*
- *Concepts and questions introduced one point at a time.*
- *Use an appropriate level of language for each individual.*
- *Provide a written copy of the key points (use colour where possible).*
- *Combine words and pictures wherever possible.*
- *If possible, encourage the person to take their own notes so they can check back with you.*
- *Explore other ways of providing information if written and/or verbal information do not work (*e.g. *video, audio, pictorial).*
- *Use diagrams and flowcharts wherever possible (at least have several different formats prepared).*
- *Ask the person to repeat back frequently to confirm understanding.*
- *Utilise a support person/translator, as necessary.*
- *Allow enough time.*

Furthermore, for researcher perusal these author provided a list of reflective questions:

- *Did I provide all the information needed?*
- *Could the information be presented in a way that is easier to understand (*e.g. *visual aids, or with simpler language)?*
- *Have I fully explored all the different methods of communication?*
- *Did I ensure the right supports/people were in place in order to prevent coercion?*
- *Have I explained all the risks and benefits?*
- *Did I allow enough time for questions?*
- *Did I check back frequently enough?*
- *Was the environment appropriate/conducive?*
- *Have I documented the consent process thoroughly?*

Taua et al. (2014) recognise how the basic frameworks for seeking informed consent from potential participants should not differ dramatically for any person, as there is a level of risk for all participants in research. It is critical, however, that researchers recognise the higher levels of vulnerabilities in the intellectually disabled population, especially those with a dual diagnosis and ensure that their recruitment processes are rigorous and respectful. Research with people with intellectual disability should maximise the benefits of the research and minimise the risks, and those who are to conduct the research should be competent to do so, and if needed, be appropriately supervised. Researchers must not only be vigilant in listening to the communications of their research participants but they must hear what they are saying. Researchers must ensure that their research approaches can be flexible enough to concur with changing needs of research participants.

Informed Consent Gaining and Healthcare

In terms of the prevalence of health conditions, individuals with an intellectual disability have poorer health than others (Emerson, 2009). Entitled to be treated with dignity, respect, honesty and be involved in decisions about their health and well-being, it is well known that people with intellectual disabilities experience challenges in this regard (Krugman, 1986; Resch et al., 2010). Specifically healthcare access and healthcare participation arise as prominent issues of vulnerability for this population group (Philips, 2016; Wark et al., 2017). For those supporting people with intellectual disabilities there is a necessity to place more attention on care needs, access to healthcare, preventive care and health promotion (Lafferty, O'Sullivan, O'Mahoney, Taggart, & van Bavel, 2016; Sheerin, 2011).

Wark et al. (2017) sought to understand informed consent when supporting individuals ageing with intellectual disability to participate in developing their own health and support programs. Indeed, challenges in the provision of oral healthcare to people with intellectual disability have been acknowledged as physical dexterity, impaired sensory functioning, communication and behavioural problems (Knibb, 2010). And notably, in the provision of healthcare, the presence of cognitive disorders have traditionally been synonymous with critical impairment of decision-making abilities. Subsequently, a long-standing culture of paternalistic practices have existed and for some people remain evident, especially so when those providing services to people with intellectual disabilities have limited experience of intellectual disability.

The following demonstrates how the attitudes and practices of healthcare professionals can impact the informed consent experience of people with intellectual disabilities. In aiming to identify the main approaches adopted by dentists in a French study, Camoin, Dany, Tardieu, Ruquet, and Coz (2018) found a 'reassuring attitude' to be the main approach that ensued when treating an anxious child with intellectual disability. Four topics were discussed, first contact with the patient, information, attitude towards the patient and outcome from the practitioner's viewpoint. The coding procedure used thematic content analysis. In all twelve dentist participant's, eight women and four men (mean age = 42.5), three had an exclusively hospital practice, three had a private practice, and six practiced in both settings. Regarding experience, four practitioners had less than 5 years' experience, six practitioners had over 15 years' experience, and two practitioners had between 5 and 15 years' experience. All practitioners interviewed declared that they informed the patient about what was happening, from the start and throughout the session. This information was conveyed by various means (verbal and non-verbal communication) and various approaches (distraction, tell-show-do, transitional object). Different communicational strategies used were:

- ***Tone of voice****: 'I mainly use a soft and empathetic tone*', *'my voice is calm, composed and even' (male, more than 15 years' experience, private practice).*
- ***Tell-show-do****: 'I show the patient the mirror, I make them touch it with their fingers, and then together we put it in the patient's mouth' (female, more than 15 years' experience, private practice); 'I always show the patient the*

instruments and let the patient touch them before I put them in their mouth' *(female, less than 5 years' experience, both private and hospital practice).*

- ***Use of a transitional object*** *(cuddly toy): 'If the patient brings a cuddly toy, it can also be used to show that the mirror is harmless' (female, between 5 and 15 years' experience, private practice).*
- ***Distraction****: 'Did you have a good holiday?' (female, between 5 and 15 years' experience, both private and hospital practice). 'I tell him a story to distract him, with a knight or a princess for example*' *(male, between 5 and 15 years' experience, hospital practice).*

These strategies demonstrate a variety of approaches and various mechanisms promoting relations between practitioners and children with intellectual disabilities. Worryingly, the practitioners within the study reported that if an ethical dilemma arose, and the patient refused care or had to be restrained, ethical values of patient autonomy would be sacrificed, under the realms of beneficence and non-maleficence, when clinical decisions were made.

Similarly, Goldsmith, Skirton, and Webb (2008) conducted an integrative literature review examining how consent was obtained from people with intellectual disabilities for healthcare interventions. Time limits set were publication between January 1990 and March 2007, encompassing 17 years of research with adult populations. The data reflected the opportunities and processes that intellectually disabled people demonstrated within consent to research, consent to treatment or (indirectly) consent to taking medication, while some data reflected hypothetical vignettes and some 'real-life' situations. Overall, the integrative review findings highlight the negative attitudinal responses as a main barrier to obtaining informed consent by healthcare staff. Several of the included studies reported that staff assumed that individuals with intellectual disabilities were unable to consent to treatment, and one study demonstrated that staff were unaware of guidelines relating to consent. Not surprisingly, assumptions of staff in this review demonstrate the prominent attitude of the status approach, all or nothing attitude to gaining informed consent. The review recommends a functional approach to assessing capacity for the purpose of obtaining informed consent recognising the complexity and nature of the decision need to be taken into account (Goldsmith et al., 2008).

Therefore, whether or not capacity to consent is achieved depends on the effort to 'tailor' the relevant information to the abilities and needs of the individual concerned. A significant point raised in this integrative review recognises how professionals are obliged to comply with their country's legal requirements; in practice, however, this may cause problems due to the time needed to maximise the potential for capacity in many people with intellectual disabilities. Future research into informed consent in people with intellectual disabilities is needed using real-life situations which are more likely to be familiar to the participants than hypothetical vignettes.

In 2013, further developing the theme of gaining informed consent with real-life situations, Goldsmith, Woodward, Jackson, and Skirton (2013) conducted a primary qualitative study using an ethnographic approach. People with intellectual disabilities were eligible for this study if they were aged 18 years or over, able to consent to participate in research, not affected by acute physical health problems, and not currently under the care of the local mental health team. The final inclusion criterion was the requirement for a routine blood test (e.g. for monitoring blood sugar control) within a few months of recruitment.

Participants' age ranged from 27 to 65 (mean 45). Half (50%) lived in a shared house (supported living), with the remainder either living at home with parents, living independently with support, or living along with informal family support. Participants with severe or profound intellectual disabilities were excluded, and this limits the transferability of the findings. Twelve of the 14 participants were single.

Observations and interviews formed the methods of data generation. Six participants were observed having one blood test, the observation period ranged from 3 to 6 min. All participants observed having the blood test were due to have blood tests as part of their routine medical care. All six participants were well known to the health professionals who performed the blood test. Health professionals included phlebotomists, healthcare assistants and registered general nurses. One semi-structured interview was conducted with 14 participants lasting between 12 and 35 min. All participants were offered the opportunity to bring a supporter to the interview and ten did so.

Consultations and interviews were video- and audio-recorded to ensure accurate transcription and enable observation of non-verbal behaviour. Data analysis was approached in an inductive way, considered appropriate for an exploratory, descriptive study guided by Braun and Clarke frameworks (Braun & Clarke, 2006). In all, the researchers identified six key themes; the patient in the healthcare context, information and knowledge, the consent process, behavioural characteristics, strategies and coping mechanisms, and 'the self'. Significantly, researchers noted that the consent process did not appear to be fully followed in any of the consultations observed in the taking of blood. In some cases, adequate information was provided. However, in the majority of cases, the health professional did not check that the participant understood the information given; this is an essential requirement for informed consent.

Goldsmith et al. (2013) reiterate the strength of their 2008 findings adding how personal qualities and experiences may influence the consent process; factors such as a person's place of residence, previous health experience and opportunities to make their own life choices all contribute to the individual's ability to consent to healthcare interventions.

In this study, the health professionals knew all participants described as 'experienced' patients. This may have led the health professionals to make assumptions concerning consent. As this study was conducted in the UK Goldsmith et al. (2013) noted that these assumptions would not be sufficient to fulfil the requirements of the Mental Capacity Act (2005), as it is the responsibility of the person carrying out the procedure to ensure that valid consent is in place at the time and this should include provision of relevant information. The right to self-determination and the right to full disclosure are major components on which informed consent is based (Grove, Burns, & Gray, 2014; Polit & Beck, 2004).

In addition, in the Goldsmith et al. (2013) study, there are two points worth highlightening (1) people with intellectual disability lack experience in decision-making, and the affect this has on their functional capacities with regard to informed consent and (2) clearly expressed their information needs with regard to their healthcare; they required clear, accessible information, with any verbal explanations being simple and without jargon.

Most notable, in Goldsmith 2013 from the 2008 study is the change in attitude of staff, in the belief that people with intellectual disabilities seek information and consent to healthcare procedures. These studies demonstrate the need to ensure there is greater awareness of increasing opportunities for effective communication to ensure that intellectually disabled people have choice, are in control and active in decision-making regarding their life choices. Nevertheless, even with the global and philosophical impetus of supporting decision-making, particularly with the implementation of the UNCRPD, current research reports continue to highlight challenges of implementing such moral and ethical principles.

Conclusion

Over the years consent theorists' have and continue to strive to illuminate and develop both the simplicities and intricacies of informed consent. An overview of historical contexts of consent theory, the impact of the bioethics and the evolving definitions informed consent lead to a current representations of informed consent both as a process and as an interactive cycle.

This chapter has presented informed consent as a dynamic, contextually driven, respectful approach to viewing people with intellectual disability primarily as decision-makers, inextricably linking informed consent with supported decision-making and rights.

This chapter presented a new way of thinking about informed consent and the role of communication and interaction. Figures 14.2 and 14.3 present an understanding of the components of informed consent asserting the importance in developing meaningful relational interactions in time and overtime to enhance mechanisms developing engagement in disclosure, understanding, voluntariness, competence and consent.

Building on such premises, the authors acknowledge the need for safeguards ongoing process and maximising human potential in supporting people with intellectual disability to identify and act on their will and preference.

Recommendations

There is a need for persons with intellectual disabilities, policy makers, legislators, service providers and supporters, to recognise how processes and interactions of informed consent maximises human potential.

People with intellectual disabilities need to have meaningful involvement at all levels in all aspects of decision-making and informed consent which affects their life choices.

- Persons with intellectual disabilities be included in education, research and philosophical debates exploring what informed consent means to them in their lives.
- Perspectives of both intellectually disabled people and those who support them to be established determining what exactly family, circles of support, citizenship, friendship and/or professional assistance looks like and how they work to ensure honesty, transparency and clarity when determining roles and functions in supporting people to make informed decisions.

As policy and legislation continues to develop in response to the needs of people with disabilities progress needs to be monitored and evaluated from the perspectives of all stakeholders. To continue driving the human rights agenda, building on the work of the UNCRPD to enable people with intellectual disabilities to take their rightful place in society as active citizens.

Service providers ensure that reasonable accommodations are afforded to people with intellectual disabilities so that they are equal members of their society.

In maximising decision-making support services need to ensure that meaningful interactions are incorporated in practices central to successful processes and interactions.

There is an onus to ensure explicit structures and procedures are utilised to enable the person to make decisions.

Individuals who support persons with intellectual disabilities must engage trustful relationships, aiming to support the person to explicate their will and preference to maximise human potential in decision-making. And when necessary ensure the availability and delivery of information about reasonable accommodations to enable the person in providing informed consent.

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