A Theory of Assent
A Working Paper of the Project:
Enhancing Interaction in Group Homes
A Collaboration between the NSW Department of Community Services and
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Abstract
This paper sets the concept of assent amidst a number of better defined, well established
concepts in community service: e.g. "duty of care", and "dignity of risk". Assent is, in fact,
conceptualized as a "space" between three dimensions or variables – duty of care, dignity of
risk and "communicative aperture" (the latter being itself a composite rating of interactional
"meaning potential").

We argue that the "zone of probable assent" can be regarded as a context sensitive (i.e.
changing) domain of discretionary power. It differs from consent in its relativity, its reliance
on a number of points of view or judgements, and the relevance it is likely to have to
extending quality of life choices as distinct from legal and medical processes.

The paper aims at contributing to, and stimulating, discussion. Beyond this discussion phase,
other developments appear close to realization. For example, by formalizing the spatial
metaphor – viz. zone, dimensions, aperture – it seems likely that a series of scales could be
combined to arrive at a "rating" (a quantity) as a working 'tool' for representing the extent of
the "zone of probable assent" in relation to given individuals and circumstances.

Introduction

Assent is an extension of the legal requirement of consent. Assent refers to the domain
of discretionary choice that must still be available to those individuals who have a
disability, but whose experience of residential life, and whose power to choose over
the way they participate in institutional and community activities, should not be
overlooked. The key characteristic of assent is that it must be interpreted, much more
than consent, in a variable, context sensitive, or relative way. Whereas the law
operates as if consent is an absolute in achieving an individual’s participation in many social processes, assent draws attention to itself as a variable balance between two potentially opposing principles – namely, "duty of care" and "dignity of risk" (pertaining to life choices). This is because assent invariably involves some ‘other’ making judgements about the subject's power to judge. For consent on the other hand, considering the subject’s power to judge is confined to the stage of designing the consent forms, and to the atypical case – e.g. where someone needs to decide whether an interpreter is required.

We are all trained to observe the needs of consent. It is codified in the law, and research committees, universities, hospitals and governments are familiar with the process of establishing consent. Some bodies, such as ethics committees, are defined by the task of protecting the integrity of the process of consent. In this sense, consent is explicit in law and highly visible – certainly it is forced upon the consciousness of all of us working in community based projects. By contrast, assent is only just becoming a visible legal concept, and consequently, it might be thought of as an issue implicit in the running of any government support service. It is implicit in that it is a concept familiar to those who work in the area of disability services, aged care, paediatrics or education (who are confronted daily with practical judgements about the value of a subject's choice), but it is yet to be turned into a clear concept with the defined boundaries of a legal definition, or the practical character of an institutional tool.

In these areas there is certainly an increasing call for carers and researchers to incorporate the assent of subjects as well as the consent of parents, guardians or other relevant third parties, into their work, and these moves have been codified in various policy statements (e.g. World Medical Association 2000; American Academy of Pediatrics 1995). However, research shows that procedures for obtaining assent are seldom described in detail (e.g. Sifers et al 2002). Often assent is assumed to exist wherever there is no dissent (a practice which is criticised for instance by the US National Bioethics Advisory Commission 1998). Where attempts are made to be explicit about the difference between consent and assent, they tend to be distinguished on the basis that consent is construed as something written, whereas assent is given
verbally (e.g. Adewumi et al. 2002). Assent in the context of those with reduced capacity for decision making tends to be construed as something that is tailored “to the sensitivities and abilities” of the subject (e.g. Erb et al. 2002). While it is indeed important to tailor requests for assent to each subject, expressing it in this way runs the risk of implying that what is at issue are self-evident attributes of individual subjects. We will argue below that assent needs tailoring to the dyad, or social group involved – perhaps the researcher and the subject; or perhaps the parent, carer, subject. It involves assessing in a principled way not only the abilities of the subject, but also the symbolic resources shared between the subject and carers or researchers.

In this paper, we are proposing a way of interpreting and implementing assent. The nub of the issue is not just the implementation at law. A law can easily be promulgated, but that does not mean that it can be enacted within the contexts to which it is relevant. The crux of understanding and implementing assent is being able to conceptualize it in such a way that others can share in the process, interpret it in a sound practical way, and apply it amidst the changing circumstances of different institutions, different homes/group homes, and in relation to different individuals (with unique combinations of experiences, ability and inclination). This is just a first step in a necessary development on community thinking – that is, being clear about the concepts; being able to explain the reasoning behind a decision, or a general policy.

Furthermore, while the notion of consent is based on the assumption of autonomy and protection, and other obligations which guardianship naturally and legally involves, the notion of assent involves a paradoxical trade off between three main concepts. First of all, as above, is the duty of care. The second has been referred to as the dignity of risk; and the third is what one might call the "zone of probable assent".
Dimensions of Assent

Briefly defining these three concepts, we take duty of care as given for the moment, and move to the second, dignity of risk. Any individual living in a group home should be able to access the experiences of the community to the extent that his/her well being, privacy and peace of mind are not placed in unreasonable risk. But, at the same time, the range of experiences accessed must not be diminished or closed off because there is some, albeit slight, risk in what other community members might regard as day to day living. Humans, as community members, have the power to make certain kinds of choices and to organize their lives around the give and take of their choices and risk taking. The value of this notion, dignity of risk, can be seen when we think of the way in which the duty of care could, in absolute terms, lead to a human having a very diminished quality of living, i.e. if no risks at all were encompassed by the guardianship.

So, between the duty of care and the dignity of risk, there is a zone of possible variation concerning the degree to which an individual, in this case, a group home resident, can communicate his or her wishes and decisions about day to day domestic and community activities. Given that communication in a group home may not be so direct and unproblematic as it might appear to be in other households, establishing what kind of decision making has gone on, and the degree to which the resident has been explicit about his or her wishes, may be difficult. There must be a fuzzy boundary around the notion of resident assent. But that fuzzy boundary, which one might call the zone of probable assent, has to be understood against:

- the activity which is being considered,
- the chances that the activity would be seen to enhance the life of the individual - including the power of the activity to provide new opportunities later on,
- the household/network balance - the fact that activities of one member of the household may well change the dynamic for both communication and stability within the living space of a particular group home.
All of this may be represented in a diagram of communicative aperture and the zone of probable assent (see Figure 1. Dimensions of Assent). What we have here is two divergent lines, and we can think of these as representing two pressures: over and above, there are the risks of disturbing privacy and peace, and even the health of an individual or group. Below the line there is the pressure to enhance the quality of living, and the obligation to remain open to what might be a marginal risk, but a considerable opportunity for the individual, or some individuals in the household. Different members of the household will, through varying potential for communication, have differing zones of probable assent. That is, they will vary in their domain of assent because they will be differently placed along a cline of communicative potential.

These variations between one household member and another are a function of the communicative certainty that those living and working in the house can establish about the wishes and experiences of the house members. Such a zone of probable assent depends on the awareness of, or construal of, behavioral opportunities being offered. A crucial question is of course: To what extent then will a resident see the implications of the activity to which she or he has complied? So too, judgements of inclination, enthusiasm, and communicative ability, and the ramifications for the household, are all pressures that change positions along this cline of probable assent. The communicative aperture is different for different individuals. The household network can be in different degrees of precipitousness; that is, one issue will disturb one house more than another, and the modes of communication available to the house residents will vary. All of these establish the communicative aperture, and where along this aperture a house resident is likely to be situated.
Variation in Assent

If we move to the second diagram (Figure 2.), we can see the situation with all these related factors brought into the representation. The arrows in this diagram constitute two axes. The higher one is for the individual: with this axis we are representing assent from the point of view of the individual. The lower axis is for the individual as a network member: we can think of the individual in relation to networks of current relations within and beyond the house. It is important that we take both these axes into the process of establishing the viable zone of assent.

The ellipses in this diagram represent different positions along the cline of assent. Communicative aperture is at one end, and different points create different zones i.e. different breadths of participatory or discretionary power which can be interpreted as the power to give assent. We can see, for instance, that the individuals in group 5 would be those for whom the difference between assent and the discretion used by the guardian in consent is minimal. The difference is minimal because you can ask the person and be confident of the response being the exercise of discretionary power akin to consent at law.

Group 4, group 3, and group 2, represent different degrees of mediation. Here mediation relies on other sources, different kinds of evidence and report. In group 2 you may have to infer the assent or disavowal through unfocused behavior, i.e. the communicative behaviors that many might not see as communicative at all, e.g. by avoiding contact, going to their room. This, within the ensemble of an individual's behavior, might be interpreted as disquiet over something that was done, or was possibly going to be done.

In group 1, we have those who might only be able to express some indexical sign: their bodily reactions might indicate their antipathy to what is, or might, be going on. This is a form of semantic behavior that, within the profile for that person, in that household, for that network, can be read as registering a kind of assent or dissent. So in this modified way we are able to see, individual by individual, a variation in kinds
of assent potential, what they can achieve communicatively for others to establish their domain of choice.

Added to the above, those working with assent need to be able to set the communicative behavior of these different groups into the specific context of the social networks that the individual needs to negotiate: first of all, within the group home, and second, within those networks that might take a resident beyond the home into certain kinds of work, travel, visiting the shops, parents, and others in their lives.

We have, in the second diagram, the two kinds of global pressure mentioned at the outset. The first is the interpretation of variable risks, which is the obligation of all people interacting with other community members, but particularly those interacting as institutional representatives in a group home, organizing group homes, and considering research. And from the other side, we have the notion of widening opportunities, with inevitable risks (of varying degree). Opportunities might well be offered by parents, institutional representatives, and those who have 'insider' and/ or expert knowledge to bring to these assessments.

**Conceptual Background**

These conceptualisations are directed to establishing a balance akin to equipoise, a term familiar to those working with clinical trials in medical research. Equipoise is a complex notion where, traditionally, the medical advisor must establish that a new type of treatment is likely to offer a better balance of risks and benefits than standard treatment. In recent years the medical community has begun to consider equipoise not so much as the mental state of an individual expert, but as a joint position, negotiated through interaction (between experts, between clinicians and patients and their families, or within the broader community) about the likely favourability of some risk/benefit ratio (Lilford 2001; Gifford 1995). This is a move that makes equipoise more relevant to caring for people with disabilities. In the case of group home residents, the composite of the context has to strike a balance between the duty of care, the dignity of risk, and the enhancement of the quality of living through the incorporation of new activities and widening social networks into the experience of
those settled in group homes or other institutions. What we have discussed so far sets out the sub components of this "equipoise", including the perspectives one might have of the individual (classified by groups 1-5), and of the individual's most immediate memberships in the home.

We have taken the "zone of probable assent" through analogy with the methods of Vygotsky (1978), the Russian psychologist, who, in talking about learning, emphasized that any concept that the student could manage without difficulty was in some way behind where the student should be. The "zone of proximal development", for Vygotsky, was the key to understanding the conceptual potential for learners: namely, that

- only by extending one's current range could one be said to be actually learning,
- only by interaction with others could the apprenticeship of social experience mean that the individual was introduced to new social processes.

Vygotsky emphasized that in interaction with another with more knowledge, or greater experience, and only by interaction, the individual can do so much more than in isolation. The measures of isolated performance, for instance IQ tests, are not measures of a human's potential to grow conceptually. The potential to grow conceptually, one's zone of proximal development, did, according to Vygotsky, vary independently of other measures of isolated (or non-interactive) performance (viz. I.Q.).

The analogy with Vygotsky's learning theory cannot be pushed too far for fear of making it appear that we are making idealistic or unrealistic expectations about autonomy. Nevertheless, one of the main points of the discussion of assent is to engage with the idea of potential; and it is not just potential to make one's own decisions, but potential for people to engage with the community and, thereby, extend what we currently believe might be the limit to a person's potential. We come back to the idea that it is not enough to confine someone to his or her safety zone (a popular spatial metaphor of behavioural range!), whether conceptual, physical, social, or domestic, and think that somehow we have done as much as we are obliged to do with respect to the individual's social network.
The critical issues for managing this composite, this equipoise, are related to the trialling of new activities and new communicative strategies, 'trade offs' and 'checks and balances'. This trialling of new activities and communicative strategies can be divided into three phases. Firstly, there may need to be an explicit sequencing of new activities and communicative strategies; secondly, there is the need to set a time frame, with a review program; and lastly, there must be a redirection plan. Our recommendation will be made in terms of these three phases. By being explicit about the structures by which initiatives can be offered and trialled, all those involved in the context of care are assisted. The residents have a mechanism by which novelty can be brought into their social networks; the carers and managers can point to the structure as the protection in place for ensuring that feedback (and correction) becomes a channel for assent/dissent.

Such ideas are hardly new: when trialing new activities and communicative strategies, it is important to set out, ahead of implementation, an explicit time frame and sequence of steps so that there is no ambiguity about what was implemented and what stage a particular policy happens to be at. Related to this, and following from this is a desist strategy that allows you to go back on what you have done and change directions if it is not working. This desist strategy is formalized before any new processes for the individual or the household are introduced.

In this second diagram we can see the equipoise between the possibility of perturbing the social network or the individuals placed within the group and the responsibility for generating proactive contexts, i.e. not always remaining within their routine. Maintaining the status quo, as Vygotsky put it, is not education, it is merely a method of keeping people where they are. The notion of assent may well open a communicative aperture onto the possibility of change for individuals in a network which often has special difficulty in dealing with change. This system is so in need of stability: the staff change, the residents change homes, someone might be hospitalized, and routines might be changed. All the pressure in this work is on how to establish stability, and continuity in the home. In the face of the factors which
constantly threaten routines and stability, and in the context of new residents, the ideas of greater expression of choice and innovation may seem unrealistic.

We argue, however, that these conditions are precisely those in which it becomes crucial to be explicit about *assent*—without such clarity of purpose, the priorities of community service can hardly be expected to encompass the idea. It may be important for establishing harmony in the household that there be some mechanism for letting *assent* have more of a role. This may appear idealistic, but it may turn out to be practical, as well as required by law.¹

**Extending the Meaning Potential of Assent**

The interests of all stakeholders—residents, parents, carers, community service managers—can only be enhanced by being clearer about the terms of *assent*, especially when much of the responsibility for *assent* may already be taken, implicitly, by experienced staff in community service areas. Where there is responsibility, it is better that there be operational guidelines (i.e. to protect those who take an empathetic initiative already). In relation to those for whom *assent* seems baffling and impractical, discussing the issues is the first step to changing consciousness. And no area of debate appears to us so subject to prejudice and therefore, so often in need of a fresh evaluation as debates surrounding "human potential".

In the next phase of the discussion of *assent*, we imagine a wider range of contributors will assist in turning the dimensions of the concept into a practical tool in the day to day exchanges of professional carers, parents/guardians, and government service managers. It is not unrealistic to expect the future discussions to produce a quantification of the dimensions of care, opportunity, network support, and communicative profile.

¹ These issues should be considered in the light of our paper "Group homes as Social Networks", in particular, the discussion of stable/static/and *homeostatic* managements of change.
Such a tool will usefully complement the work already developed on compatibility scales and "behaviour as communication" in relation to group homes and challenging behaviours. An important question also will be how the role of *assent* may affect the range of possible research, as permitted by Ethics Committees. Clearly, researchers will need to demonstrate, unequivocally, the ways in which their research creates a new possibility in the living of the research participant. A new balance will need to be found in the methods of research.
References


Ferguson, D. *Interpretation of Behaviour Sheet* Department of Community Services.


World Medical Association *Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects*. Adopted by the 18th WMA General
Assembly Helsinki, Finland, June 1964. Latest amendment 52nd WMA
### Appendix: Gauging Assent

<table>
<thead>
<tr>
<th>Degree of equanimity</th>
<th>ACTION for each group on approaching about participation and consent</th>
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| high equanimity
(= low upsettability) |
| Parent must consent | Parent must consent | Resident must consent (verbal ok) |
| Resident must be observed for discontent/ dissent | Resident must assent thru carer/parent | Parent should assent and sign |
| Avoid selecting | Parent must consent | Resident must consent (verbal ok) |
| Resident to assent thru carer/parent | Resident must be observed for discontent/ dissent | Parent should assent and sign |
| low equanimity
(= high upsettability) |
| low | medium | high |
| person is seldom interpreted as making a choice re complex events | network-dependent interpretation as making a choice re complex events | network-independent interpretation as making a choice re complex events |

2 For “parent”, read “parent, guardian, or person responsible” throughout