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Substitute Decision-Making for Adults with Intellectual Disabilities Living in Residential Care: Learning Through Experience

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Abstract

In the UK, current policies and services for people with mental disorders, including those with intellectual disabilities (ID), presume that these men and women can, do, and should, make decisions for themselves. The new Mental Capacity Act (England and Wales) 2005 (MCA) sets this presumption into statute, and codifies how decisions relating to health and welfare should be made for those adults judged unable to make one or more such decisions autonomously. The MCA uses a procedural checklist to guide this process of substitute decision-making. The personal experiences of providing direct support to seven men and women with ID living in residential care, however, showed that substitute decision-making took two forms, depending on the type of decision to be made. The first process, 'strategic substitute decision-making', paralleled the MCA's legal and ethical framework, whilst the second process, 'relational substitute decision-making', was markedly different from these statutory procedures. In this setting, 'relational substitute decision-making' underpinned everyday personal and social interventions connected with residents' daily living, and was situated within a framework of interpersonal and interdependent care relationships. The implications of these findings for residential services and the implementation of the MCA are discussed.

Keywords

Substitute decision-making; Best interests; Intellectual disabilities; Care ethics

Introduction

For much of the last century, people with intellectual disabilities (ID) were often geographically and socially isolated [24], and their opportunities to make any decisions about their own lives were severely restricted. Increasingly, however, the philosophy of an 'ordinary life' [3, 20, 33] has gained acceptance, advocating the provision of support that enables men and women with ID to live in accordance with their own wishes and values, and within their local communities.

This 'ordinary life' philosophy has been embraced by government policy in the UK in developing services, and has informed the White Papers, *Valuing People* [10] and *Our Health, Our Care, Our Say* [12], which have been built around the principles of rights, independence, choice and inclusion. For some men and women with ID, however, the nature of their disability means that they will be unable to make one or more autonomous decisions at certain points in their lives, regardless of the support they receive. Set against service frameworks founded upon independence and self-determination, this will likely give rise to

dilemmas in which the conflicting discourses of autonomy, protection and risk might lead to restrictions in the range of choices made available.

The Mental Capacity Act (England and Wales) [26] (MCA), which comes into force during 2007, introduces a framework for decision-making that acknowledges that, at any one time, more than two million adults will lack the ability to make one or more decisions about their own lives [9]. This figure includes not only some people with ID, but also those with severe mental illnesses, dementia, brain damage, head injury, delirium, or substance misuse (Code of Practice, para. 4.12). The MCA's principles are in line with current government policy: they state that the starting point is always that these adults are able to make decisions for themselves about their health, welfare and finances (MCA, s. 1(2)). Someone is only unable to make a specific decision if he/she has an "impairment of, or disturbance in the functioning of, mind or brain" (MCA, s. 2(1)), which leads him/her to be unable to understand the information relevant to the decision, retain that information, use or weigh up that information as part of the decision-making process, or to communicate his/her decision (MCA, s. 3(1)). If a judgement of incapacity is made, any substitute decision made on that person's behalf must be in his/her 'best interests' (MCA, s. 1(5)). The MCA's Code of Practice [27] provides a 'best interests checklist' to guide this process, and the substitute decision-maker has a legal obligation to take into account certain factors. These include:

- Whether capacity will be regained and, if so, when
- Whether the person can be permitted and encouraged to participate in the decision, regardless of their lack of capacity
- The person's past and present wishes, feelings, beliefs and values
- The views of other people who are deemed practicable and appropriate to consult
- All other circumstances deemed to be relevant

(Adapted from Code of Practice, para. 5.13)

Determining the person's 'best interests' through this set of formal and universal procedures must underpin all substitute decisions involving 'acts in connection with care and treatment' (MCA, s. 5). The 'best interests checklist' applies, therefore, to a broad range of everyday decisions (including decisions about which clothes to wear, what to have for dinner, and how to spend the day), in a variety of health and social care settings. Implementing the MCA, then, involves integrating these procedures into guidance that governs practice in particular settings. One such setting is long-term residential care for adults with ID. Epidemiological studies show that up to 567,000 men and women in the UK live in group homes, sharing with other people with ID, and receiving assistance from 'support workers' [16, 17, 25, 30]; they are the predominant residential arrangement [14]. In group homes, the implementation of the MCA is expected to involve substitute decision-making procedures, relating to a range of everyday decisions, being incorporated into individual care planning, in line with National Minimum Standards in residential care services [11], and guidance in the MCA itself (Code of Practice, para. 6.25; 6.34). These plans, which are drawn up with the person and his/her family, are complemented by daily care records, used to document the decisions made. The MCA requires that a support worker approach each substitute decision with primary regard to the 'best interests checklist' and, therefore, the successful implementation of the MCA in group homes will be dependent on support workers identifying with this statutory framework, and the care plans informed by it. This paper will critically examine this link, by drawing on personal reflections of the experience of making substitute decisions in this setting.

The Methodology: Reflecting on Personal Experience

I was employed, over a 3-month period, as a relief support worker in a group home for four women and three men with ID, run in South Cambridgeshire by an established charity¹. Four residents had additional physical disabilities, mental health problems, autism spectrum conditions and/or epilepsy. All residents had care plans that outlined their interests and specific needs, and the group was supported by at least four support workers during the day, and by two during the night. The aims of this period of employment were to, first, gain understanding of the experiences of providing support to a group of people who were dependent on staff to assist them in almost all aspects of their daily and social functioning, and, second, to provide a real-world insight into all aspects of the process of making substitute decisions. My personal reflections on my experiences of support work in this setting were captured in a diary that I completed after each of my shifts, detailing the ways in which I provided support and engaged in substitute decision-making. The entries also include reflections based on conversations with other support workers. This reflects the nature of the induction process in this setting, which relies primarily upon on-the-job training and peer support. My employment as a support worker was the first element of a broader project for which ethical approval was granted from the Cambridge Local Research Ethics Committee (LREC). In addition, the employer's regulations requiring anonymity for all staff and residents were adhered to. In the diary, residents and support workers were referred to using pseudonyms, and these are reproduced in this paper.

Operationalising Substitute Decision-Making

The MCA characterises substitute decision-making as a set of individual, discrete interventions, made for the person judged to lack decision-making capacity, with a clear, and expected, outcome that can be justified objectively by undertaking a 'best interests' determination. This approach reflects common law jurisprudence, which developed the procedures for substitute decision-making in two ways. First, common law cases were extended, over time, to substitute decisions involving serious medical treatment and major social welfare interventions, such as long-term accommodation placements. Second, these cases conceptualised the substitute decision-making process within two relationships: the doctor–patient relationship, and the group consultation or case conference [13]. However, the substitute decisions that arise in residential care are more extensive, and are made in social settings characterised by relationships which differ from these types. Understanding how substitute decision-making is operationalised in this setting requires these substitute decisions, and the ways that they are made, to be examined.

We show that substitute decisions were operationalised through two different processes, depending on the type of decision, and we characterise these two processes as 'strategic substitute decision-making' and 'relational substitute decision-making'.

Table 1 shows the substitute decisions that I made as a support worker, and categorises them according to the substitute decision-making process through which they were made. To understand why particular decisions 'fit' naturally into either a strategic or relational process requires both processes to be explored in detail.

¹The personal experiences described in this paper are those of MD, and the paper has been written in the first person to best characterise these experiences. However, all three authors contributed to the writing of the paper.

Strategic Substitute Decision-Making

Consultation and Detachment—The decisions that underpinned a strategic process of substitute decision-making were operationalised in a consultative and professional manner, and detached from everyday staff-resident interactions in the home:

“We all sat outside [on the patio] which is, I guess, the staff area... We talked about a day out for all the residents, ideas were discussed and going to the pantomime seemed to be the favoured idea. The number of carers needed was discussed, the practicalities, etc. But we all thought it was a good idea, house outings don’t happen often enough.”

22nd November 2005

The decision to organise a house outing was seen as a special event, requiring consideration, planning, and an assessment of its anticipated costs and benefits. The spatial separation here is important; all support workers on duty at the time met together in a neutral space with no residents present.

While I was employed, winter influenza vaccinations were arranged for the residents. These were performed at the home by a community nurse, and involved arranging a suitable time and place to give the injection. Appointments would be postponed if a resident was thought to ‘not be in the mood’, but the decision to give the injection, for those judged to lack decision-making capacity, was determined in medical terms, and centred on balancing objectively a resident’s health and well being with the discomfort associated with the injection. Again, this was carried out in consultation with all the support workers on shift at the time; whilst the resident would be fully informed about the intervention, the decision to intervene on his/her behalf was thought through from a detached and professional perspective.

Care Planning—The consultative and detached character of strategic substitute decision-making was founded upon a professional model of individual care planning to guide the decision-making process. In residential care, individual care plans are designed to introduce the person, and his/her specific needs, beliefs and values, to members of staff. They are intended to enable support workers to get to know each person as an individual, and to make decisions and interventions accordingly. In the home in which I worked, these care plans were written in the first person, giving the impression that the residents had written them themselves, and were reviewed regularly with the resident, his/her key worker, his/her family and the home manager.

In discussing plans for a resident’s summer holiday, the support workers sat together in a space isolated from the residents:

“Over coffee at the dining table I sat round with the other members of staff and we discussed plans for Bill’s holiday. I knew that Bill loved sandy beaches so suggested that a trip abroad might be nice, but Sally didn’t think Bill would be able to travel on a plane very easily. We decided that it would be best to delay any plan until Bill’s next care meeting, so that all members of staff interested in going could suggest a list of places that they thought would be appropriate, and then these could be discussed with his sister.”

4th November 2005

Here, the process of thinking through the early stages of this decision involved adopting a procedural approach which utilised individual care planning. The decision was separated into different phases; support workers discussed the pros and cons of different destinations,

allowing them to then frame a number of possible choices in a care meeting with Bill and his sister, so that the final decision appeared inclusive. In fact, however, the practicalities of accompanying a resident on holiday, such as the number of staff required, the cost, and the constraints posed by certain modes of transport, were all managed by limiting the options from which Bill and his sister could choose.

Discussion—Whilst neither I nor the other support workers on duty at the time drew explicitly on the ‘best interests checklist’ when making ‘life plan’ decisions and healthcare interventions, the process of strategic substitute decision-making is in line with the statutory procedures outlined in the MCA and its Code of Practice. First, weighing up the benefits and burdens associated with each choice to guide an objective assessment of which outcome would be ‘best’ for the resident, and then consulting with family prior to the decision being made, is comparable with guidance in the Code of Practice to balance the pros and cons of relevant factors (Code of Practice, para. 5.62), and to seek advice from individuals who are interested in the person’s welfare (Code of Practice, para. 5.49). Second, the foundation of strategic substitute decision-making in individual care plans parallels the role envisaged for care planning in implementing the MCA in this setting (Code of Practice, para. 6.43).

The use of care plans in strategic substitute decision-making might suggest that implementation of the MCA will be relatively straightforward, as these resources are already drawn upon when making substitute decisions. However, the type of decisions which underpinned the strategic process were those decisions most closely aligned to a model of professional care. ‘Life plan’ decisions and health care interventions parallel those common law judgements, relating to medical treatment and social welfare, through which the ‘best interests’ principle developed, and was codified in the MCA. Many substitute decisions and interventions which arose within this home were not, however, operationalised through this strategic process.

Relational Substitute Decision-Making

‘Everyday’ decisions, which form the personal and social interventions that support a resident in living his/her daily life, underpinned relational substitute decision-making.

Interconnected Decisions—The relational process is characterised by a series of interconnected decisions, which could not be distinguished in any meaningful way:

“When helping Bill get dressed I tried to think through all the separate decisions I was making... I’d never thought so carefully about the process of getting dressed before – and I won’t again... it was distracting me from my job.”

21st November 2005

Here, my attempt to focus on the separate decisions involved in assisting this resident actually took away from the perception of providing good care; it appeared to impose a barrier. When thinking about support work this is perhaps not surprising; making an individual discrete decision does not fit with the ongoing process of staff-resident interaction through which residents are supported in their daily lives. Instead, relational substitute decision-making was characterised by a chain of decisions extending into the past and the future:

“About 4.30 Dave told me that he was hungry, and that he wanted a bag of crisps. This was the third time in the day that he’d asked me for some crisps. I tried to explain to him that dinner would be ready in about an hour and that I’d already got him a bag after lunch and that he shouldn’t have any more today. He wasn’t happy about it, repeating the word crisps over and over and then asking Emma if she

would get him some crisps. She also said that dinner would be ready soon and that he should wait... sure enough though he approached me again half an hour later. Again I decided that it wasn't in his best interests."

25th November 2005

Here, the decision not to give this resident another packet of crisps was made with reference to a number of earlier decisions. Drawing on our previous interactions, I framed this within my experience of working with him during this shift (I had already given him a packet of crisps), my experiences of supporting him previously (he often made repeated demands for food), and a strategic substitute decision which fixed meal times in advance for all residents.

Interpersonal Care Relationships—The relational process of making 'everyday' decisions within my ongoing interactions with the residents meant that I redefined my support work in a way that enabled me to 'relate' to individuals with whom I might otherwise have thought to have little in common, thus fostering the development of interpersonal care relationships. These relationships became the sites within which relational substitute decision-making was founded; they determined how I attached meanings and values to a resident's life experiences, informing the ways that I made 'everyday' decisions:

"Dinnertime is the only time that the whole house gets together. I supported Claire with dinner and it was a wonderful experience... We talked about life up north, her family, joked about southerners. I learnt from her, she learnt from me... it was a developing friendship... after struggling for so long I felt as if I had finally cracked it. I was buzzing. Quite an amazing feeling."

25th November 2005

Here, the sense of connecting fully with the resident was how I conceptualized appropriate support, above and beyond the task of feeding her. Transcending a relationship focused solely on a resident's dependency on me for personal and social support, to one built around shared life experiences, and common meanings and interpretations, however rudimentary or stereotypical these might be, provided the foundations for relational substitute decision-making. Interdependency within the care relationship allowed me to feel as if I 'knew' the resident, and 'understood' what he/she wanted from me:

"Putting on the TV for Claire, I tried to see what programmes she most enjoyed watching. Two minutes later she started giggling when I switched Eastenders on. Before I knew it I found myself laughing too. We often have these little laughing fits together, and I left her watching Eastenders"

18th October 2005

This scenario could, of course, be interpreted strategically—by identifying the decision to watch television, considering the different programmes available, and then judging the resident's assent to one specific choice as being indicative of her 'best interests'. However, it was, in fact, the shared experience of laughing together that guided the decision-making process, and which motivated the decision to be made in this way. A single decision to watch one television programme was embedded within our ongoing interactions, and the experience of laughing together was perceived, by me, as being at the foundation of our care relationship and, accordingly, as a point of reference for making 'everyday' decisions on her behalf. In contrast with strategic substitute decision-making, care plans did not have a major role to play in the relational process:

"Kate told me it's not always best to do that [consult care plans]... she told me that over time you'll get used to his little ways, you'll come to understand him and realise what he needs from you..."

18th October 2005

“I’ve realised that I don’t consult residents’ care plans anywhere near as often as I used to. It seems inappropriate to do so now, like all I’m doing is ticking a box to say that I’ve done it... at least for most of the residents I now feel that I know them well enough to make the right decisions anyway, and if I don’t feel confident I tend to speak to one of the members of staff who’s been there longer and worked with them before”

7th November 2005

In my experience, care plans were regarded by support workers with suspicion, and referring to them was seen as implying a personal failure in relating adequately to the residents. For me, as for other support workers, they provided a useful resource for guiding the ‘everyday’ decisions made in my first few shifts, but played less of a role in relational substitute decision-making as I gained experience and confidence.

Discussion—The relational process of making ‘everyday’ substitute decisions was embedded within interpersonal and interdependent care relationships, and not detached from them. Within each relationship, the meanings and values that I attached to our shared experiences acted as points of reference for identifying the ‘best’ decision, and care planning had only a limited and preliminary role to play. Unlike strategic substitute decision-making, relational substitute decision-making appears discrepant with professional procedures, and inconsistent with the legal and ethical framework of the MCA. Should relational substitute decision-making be seen, therefore, as an illegal and unethical approach to making substitute decisions, that acts against an objective determination of a resident’s ‘best interests’, or, do comparable analyses of care relationships throw empirical or theoretical weight behind this relational process?

Within intellectual disability research, there have been very few studies offering a substantive examination of care relationships in this setting. Instead, there has been a focus on service evaluations involving objective (e.g. [15]) or subjective [8, 29] measures of residents’ quality of life. The care relationship through which support is provided has been of importance only to the extent to which it impacts on the quality of life outcomes for residents. One notable exception is Clegg et al.’s [5] study, which develops a core typology of relationships to theorise professional care interactions. By exploring the different ways that support workers relate to people with ID, Clegg and her colleagues suggested that certain types of relationships were qualitatively better than others; however, they did not examine specifically the ways that substitute decisions are made within these relationship types.

My personal experiences of relational substitute decision-making do, however, parallel philosophical and empirical critiques of a cognitive and rational understanding of decision-making, codified in the MCA to assess decision-making capacity. These critiques draw attention to, amongst other things: (a) the role that emotions play in decision-making [4], (b) the impact of a patient’s value system on his/her medical treatment decisions [32], and (c) hermeneutic, narrative and care ethics perspectives to emphasise the importance of studying the social setting in which decisions are made, and decision-making capacity is assessed [2, 19, 23, 31]. The care ethics perspective drawn upon by Maeckelberghe [23], which exposes the role of care relationships in decision-making and the assessment of decision-making capacity, is closely related to my experiences of making ‘everyday’ substitute decisions founded in interdependent care relationships. Care ethics does indeed provide a normative framework within which relational substitute decision-making might be situated. An ethics of care “emphasises the relational character of human life” [21: 453], on the grounds that

“human beings are thoroughly embedded in a host of involuntary, as well as voluntary, supportive social relations through which we define ourselves” [22: 5]. In contrast with other ethical theories that begin with adult moral agents pursuing their conception of the good, the inevitability of human dependency and interdependency is taken seriously [21]. The process of caring, and being cared for, is then recognised as being basic in human life [28], requiring an ongoing connection between individuals [23], and demanding a place at the very heart of our understanding of ethics.

It follows that in a world characterised by the ‘relational self’, non-traditional relationships in professional care, such as parent–child relationships or intimate friendships, might be appropriate paradigms for thinking about moral decision-making. A legal and professional framework that does not incorporate a relational approach to substitute decision-making, or recognise the role played by interdependent care relationships in this process would be, from a care ethics perspective, of dubious moral value.

General Discussion

The personal experiences of providing support to adults with ID living in residential care settings showed that substitute decision-making took two forms, depending on the nature of the decision. These two processes are characterised as strategic and relational substitute decision-making. The strategic process underpinned ‘life plan’ decisions and health care interventions, and was situated within individual care plans which reflect the MCA’s statutory procedures. In contrast, the ‘everyday’ personal and social interventions, connected with residents’ daily living, were based on the relational process, and situated within a framework of interpersonal and interdependent care relationships. Relational substitute decision-making is not consistent with the MCA’s framework or professional care planning, and, instead, reflects an ethics of care.

Before considering the wider implications of these findings, it is important to note that they are based on one support worker’s experiences. The extent to which these experiences are generalisable to those of other support workers, even within this setting, needs to be considered if they are to have wider relevance. The diary entries remain personal reflections. However, the peer support approach to work in this setting meant that the participation, perspectives and opinions of other support workers were part of the operationalisation of substitute decision-making, particularly strategic substitute decision-making. Equally, these experiences aimed to provide a real-world insight into personal and professional aspects of the substitute decision-making process. By analysing substitute decision-making from the perspective of one support worker, this paper has problematised substitute decision-making “from the inside”, outlining some potential limitations of the MCA’s framework for making substitute decisions, and some conceivable pitfalls for implementation. Whilst further empirical research is required, this study provides a springboard for thinking about the different ways that substitute health and welfare decisions are operationalised in residential care settings.

These findings demonstrate that interdependent care relationships are a key element of the ways that a number of substitute decisions are made on behalf of men and women with ID living in residential care. Despite the absence of any clear statutory or professional basis for relational substitute decision-making, a care ethics framework was put forward to make sense of this process. However, whilst this ethical theory fits closely with the ways that I made ‘everyday’ decisions, and also offers a moral justification for developing interdependent care relationships, critiques of care ethics have rightly drawn attention to the fact that these relationships are not self-regulating or transparent, however intrinsically ‘good’ they might appear to be [22]. At their most benign, care relationships should

perpetuate ethical practice, but in settings where imbalanced power dynamics exist, there is little means to regulate and protect against abuse. This theoretical claim is not without substance; recent scandals in this setting, most notably the reports on abuse within Cornwall Partnership NHS Trust [6], and Sutton and Merton Primary Care Trust [7], demonstrate the need to regulate care relationships closely. So, should the findings of this study be consistent with the experiences of other support workers, how might substitute decision-making, in residential care, be regulated, such that residents are empowered to live 'ordinary lives' and also be protected from abuse?

Current National Minimum Standards in residential care are intended to reflect outcomes for service users that maximise their quality of life [1, 11]. However, we suggest that in addressing this question, the MCA's procedures may need to be incorporated carefully into new National Minimum Standards. We envisage that these Standards would then reflect the processes through which support is provided, focused on developing interpersonal care relationships alongside care planning as complementary models for substitute decision-making. In addition, the successful implementation of the MCA would require training that reinforces the role of care planning and care relationships in facilitating substitute decision-making that empowers and protects residents. In practice, this might involve support workers having the opportunity to reflect on their interpersonal relationships through the kind of personal supervision that shapes practice for other 'helpers' [18], as well as contributing to residents' care plans and care records.

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References

1. Beadle-Brown, J.; Hutchinson, A.; Mansell, J. Care standards in homes for people with intellectual disabilities. Tizard Centre; Canterbury: 2005.
2. Benayaro L, Widdershoven G. Competence in mental health care: A hermeneutic perspective. *Health Care Analysis*. 2004; 12(4):295–306. [PubMed: 15658084]
3. Caine, A.; Hatton, C.; Emerson, E. Service provision. In: Emerson, E.; Hatton, C.; Bromley, J.; Caine, A., editors. *Clinical psychology and people with intellectual disabilities*. Wiley; Chichester: 1998.
4. Charland L. Is Mr. Spock mentally competent? Competence to consent and emotion. *Philosophy, Psychiatry, and Psychology*. 1998; 5(1):67–86.
5. Clegg JA, Standen PJ, Jones G. Striking the balance: A grounded theory analysis of staff perspectives. *British Journal of Clinical Psychology*. 1996; 35:249–264. [PubMed: 8773801]
6. Commission for Healthcare Audit and Inspection. Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust by the Commission for Social Care Inspectorate and the Healthcare Commission. Commission for Healthcare Audit and Inspection; London: 2006.
7. Commission for Healthcare Audit and Inspection. Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust. Commission for Healthcare Audit and Inspection; London: 2007.
8. Cummins RA. Caregivers as managers of subjective wellbeing: A homeostatic perspective. *Journal of Applied Research in Intellectual Disabilities*. 2005; 18:335–344.
9. Department for Constitutional Affairs. Mental Capacity Implementation Programme, PowerPoint Summary. 2005.

10. Department of Health. Valuing people: A new strategy for learning disability for the 21st century. The Stationery Office; London: 2001.
11. Department of Health. Care homes for adults (18–65) and supplementary standards for care homes accommodating young people aged 16 and 17: National minimum standards, care homes regulations. The Stationery Office; London: 2003.
12. Department of Health. Our Health, Our Care, Our Say: A new direction for community services. The Stationery Office; London: 2006.
13. Dunn, MC.; Clare, ICH.; Holland, AJ.; Gunn, MJ. Constructing and reconstructing ‘best interests’: An interpretative examination of substitute decision-making under the Mental Capacity Act 2005. (in submission)
14. Emerson, E. Models of service delivery. In: Grant, G.; Goward, P.; Richardson, M.; Ramcharan, P., editors. Learning disability: A life-cycle approach to valuing people. Open University Press/McGraw Hill Educational; Maidenhead: 2005.
15. Emerson, E.; Hatton, C. Moving out: Relocation from hospital to community. HMSO; London: 1994.
16. Emerson, E.; Hatton, C.; Felce, D.; Murphy, GH. Learning disabilities: The fundamental facts. The Mental Health Foundation (Foundation for People with Learning Disabilities); London: 2001.
17. Fryers T. Epidemiological thinking in mental retardation: Issues in taxonomy and population frequency. International Review of Research in Mental Retardation. 1993; 19:97–133.
18. Hawkins, P.; Shohet, R. Supervision in the helping professions. 2nd ed. Open University Press; Buckingham: 2000.
19. Higgs R. The contribution of narrative ethics to issues of capacity in psychiatry. Health Care Analysis. 2004; 12(4):307–316. [PubMed: 15658085]
20. King’s Fund. An ordinary life: Comprehensive locally-based residential services for mentally handicapped people. King Edward’s Hospital Fund for London; London: 1980.
21. Kittay EF. Dependency, difference and the global ethic of longterm care. The Journal of Political Philosophy. 2005; 13(4):443–469.
22. Koehn, D. Rethinking feminist ethics: Care, trust and empathy. Routledge; London: 1998.
23. Maeckelberghe E. Feminist ethic of care: A third alternative approach. Health Care Analysis. 2004; 12(4):317–327. [PubMed: 15658086]
24. Martin, JP. Hospitals in trouble. Basil Blackwell; Oxford: 1984.
25. McLaren J, Bryson SE. Review of recent epidemiological studies of mental retardation: Prevalence, associated disorders, and etiology. American Journal of Mental Retardation. 1987; 92:243–254. [PubMed: 3322329]
26. Mental Capacity Act 2005. The Stationery Office; London:
27. Mental Capacity Act 2005 Draft Code of Practice. The Stationery Office; London: 2007.
28. Noddings, N. Caring: A feminine approach to ethics and moral education. 2nd ed. University of California Press; Berkeley, CA: 2003.
29. Perry J, Felce D. Quality of life outcomes for people with intellectual disabilities living in staffed community housing services: A stratified random sample of statutory, voluntary and private agency provision. Journal of Applied Research in Intellectual Disabilities. 2003; 16:11–28.
30. Roeleveld N, Zielhuis GA, Gabreels F. The prevalence of mental retardation: A critical review of recent literature. Developmental Medicine and Child Neurology. 1997; 39:125–132. [PubMed: 9062428]
31. Sherwin, S. A relational approach to autonomy in health-care. In: Sherwin, S., editor. The politics of women’s health: Exploring agency and autonomy. Temple University Press; Philadelphia: 1998.
32. Tan J, Hope T, Stewart A. Competence to refuse treatment in anorexia nervosa. International Journal of Law and Psychiatry. 2003; 26:697–707. [PubMed: 14637209]
33. Towell, D., editor. An ordinary life in practice: Developing comprehensive community-based services for people with learning disabilities. King Edward’s Hospital Fund for London; London: 1988.

Table 1

Characterising substitute decisions in residential care

Strategic substitute decision-making		Relational substitute decision-making
'Life-plan' decisions	Health care interventions	'Everyday' decisions
<ul style="list-style-type: none"> house outings holiday plans day care activities visits to family and friends meal times and weekly dinner menus 	<ul style="list-style-type: none"> influenza vaccinations medication management exercise routines therapeutic interventions: music, art, reflexology, aromatherapy 	<ul style="list-style-type: none"> personal and intimate care interventions choosing clothes and dressing house-based daily activities: listening to music, watching television and films breakfast and lunch choices beverages and snacks