

Appropriated landscapes: the intrusion of technology and equipment into the homes and lives of families with a child with complex needs.

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Within any research project serendipity plays a role. New lines of enquiry emerge often arising from the post-fieldwork dialogue between team members. In a recent project focusing primarily on children's and family's experiences of Community Children's Nursing Services (CCNS) (Carter & Coad, 2009; Coad & Carter, 2009) our attention became increasingly drawn to the impact of the technology and equipment that many children with complex needs rely on in their home. This link was, perhaps, inevitable given the first author's interest in how human beings experience space and place in health and illness (Moore, 2009).

For those parents we met face-to-face, we were invited into their living rooms – the place of welcoming and family gathering – to do our interviews. Parents frequently referred to the technological aids (e.g., postural chairs and ventilators) and medical supplies (e.g., syringes and suction tubes) they and their children relied on, revealing how ever-present these were within their home. The special postural chairs had been customized by manufacturers to make them look less 'medical': a wooden bumblebee design aimed to create a more 'child friendly' chair by reducing the impact of the functional technology. It was clear that the manufacturers had tried to make the 'techy', roboticised and frankly often scary looking devices more discreet (to avoid attention), in an attempt to make them look less discrete (distinct from everything else), and more sympathetic to a normative or ideal aesthetic of home and family life. It didn't work.

In other houses ventilators and pumps whirred and laboured and boxes full of syringes and medication stacked under the cot in which a child lay, belied the fact that the child was technology dependent. The truth was both visually and audibly apparent – there was no hiding it to us as guests. We are not suggesting it should be hidden. And yet, some parents spoke of trying to hide equipment – in cupboards, behind the sofa or upstairs out of view of visitors. To them, these objects framed the difference between their child and others. One mum spoke of how the paediatric cradle her son lay in, next to the generic 'Moses basket' of his twin sister, became the focus of visitors; they ceased to see him as a 'child', instead seeing only the cradle, framing the difference between the children. The equipment intruded into her home "imagine it in your lounge, it's ugly" and even more importantly such devices ". . . make the child disabled". Carnevale's (2007) discussion of stigma and passing has resonance here.

The home spaces of families with technology dependent children are different from other family homes, being re-constructed around the child's condition and needs (we emphasise re-constructed, because before their child's needs became apparent their homes would have been different). The home space becomes an appropriated landscape: no longer a family landscape but a landscape of care, "like a mini hospital", with some parents feeling this particularly keenly.

Children and families, and in some cases even friends, become experts in the use and administration of medical technologies. The physical (the building and contents), social (family, friends and health professionals) and symbolic landscapes (the objects and rituals) of the home then start to reflect

those of the place which all families wish to avoid – hospital. In avoiding the hospital, the family's goal is a "normal family life", for the children to feel included, cared for and safe in a family home. Though medical technology enables this, it remains incongruous and symbolic of the place they aim to avoid. For some parents their lack of autonomy and control over the appropriation of their space created resentment; there was a sense that some were not at-home within their own home.

Seamon (1979) laid down five pre-requisites for a sense of at-homeness – that feeling of being completely comfortable and secure in one's home; rootedness (a sense of familiarity and belonging), regeneration (the restorative function of place), at-easeness (the freedom to be oneself), warmth (a friendly and supportive atmosphere) and appropriation (a sense of possession and control). The presence of such technology and equipment is a challenge particularly to appropriation and therefore by turn affects at-easeness. Not only is the presence of such technology a reminder that one does not have a choice, or fully control their own space, but it reminds them of the fragility of their child's life. This is a source of constant unremitting anxiety; one father described it as living "a couple of rungs up the stress ladder". This corrodes the anchor points of ontological security, which Giddens (1990 p.92) describes as: 'the confidence that most human beings have in the continuity of their self-identity and in the constancy of the surrounding social and material environments of action'. Without the technology children would have to live in hospital, or they would simply die.

We offer no solution here. It seems fair to say that designers cannot make discreet that which is discrete and unsympathetic to a homelike setting. But it does bring to light the difficulties which families face in their own homes. We should perhaps be more appreciative of just how far the challenges of chronic illness and profound disablement spread into the lives of families. It affects their very being-in-the-world on every level; physically, psychologically, emotionally, socially, spiritually and of course, environmentally.

There will always be a tension between medical technology, function and the idealistic aesthetic of the 'family home'. Professionals should recognise that there is often a compromise; keeping a child at home means that home is subsequently changed. Some families will be able to deal with the situation by freeing up or reorganising space, or hiding away and storing technology in cupboards and boxes. In other circumstances, families who may not have the luxury of such space or resources will deal with the situation however the best they can. And they do a remarkable job of just that.

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