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Using codes of ethics for disabled children who communicate non-verbally - some challenges and implications for social workers.

Abstract

This article evaluates the use of professional codes of ethics by social workers specialising in work with disabled children who communicate non-verbally. It draws upon phenomenological interviews and other studies to highlight challenges faced by practitioners in a complex role which demands high-levels of skills and knowledge. Supporting other research, codes of ethics were rarely utilised by practitioners who typically maintain a vague appreciation while often compelled to focus upon pragmatic and quick responses to a complex role. Despite this, it is argued that principle-based frameworks embedded within codes of ethics carry important political implications. These include the potential to strengthen existing utilitarian and bioethical discourses embedded in policy or dominant professional narratives, and which can at times marginalise or exclude disabled children.

Keywords: disability; utilitarianism; social work; exclusion; ethical codes; bioethics

Using codes of ethics for disabled children who communicate non-verbally - some challenges and implications for social workers. Introduction

Since the 1970's codes of ethics have rapidly expanded among welfare professions such as social work. Codified moral frameworks can help to promote basic morals, norms and standards of behaviour, alongside values and a distinct professional identity (Butler, 2002). Despite such validity, codes of ethics have faced regular criticism. For example, questions remain as to the extent practitioners including social workers are fully aware of ethical codes, or indeed make conscious attempts to apply them in practice (Congress, 2010). Codes are arguably also more concerned with establishing rules or implicit laws of conduct, rather than

supporting moral integrity (Baines, 2013). Indeed, some studies suggest that personal reflection, collective meetings or discussions, mutual trust and reflexivity can be more effective in resolving ongoing ethical dilemmas, and that more empowered, dynamic or recalcitrant styles of agency largely 'treat ethical codes as irrelevant' (Truman, 2003: 13).

This paper draws from data gathered following phenomenological interviews with 16 statutory social workers based in the North West of England, and who specialised in work with disabled children who communicate non-verbally. As part of a broader study exploring pervasive challenges in the field, it aimed to evaluate the validity or otherwise of utilising ethical codes in social work with children with a learning disability. The paper confirms other studies which highlight a lack of conscious engagement with codified ethics. It also argues that codes may inadvertently validate disengaged practices as part of wider discourses, and struggle to support proficient skills in intricate work with a minority group who have more complex needs. The research followed ethical governance processes and gained relevant permissions.

Some practical challenges faced in work with children who communicate non-verbally

In most European countries (especially the UK) statutory social workers retain a legal and policy-led obligation to inform, involve and consult with children. This responsibility is embedded throughout assessments, formal care proceedings, or during other notable contact (for example, under the Children and Families Act, 2014). Assessments of need should be informed by the personal perspectives of the child, however challenging this may prove. Research evidence, however, indicates that children who communicate non-verbally can be quickly marginalised or even ignored by professionals, who not uncommonly prioritise verbal means of expression. This is especially the viewpoints of parents, other primary carers or fellow professionals. Subsequently, although often having alternative non-verbal or adaptive

means of communication, such children can regularly experience difficulties securing basic legal or human rights (Morris, 2005; Miller and Brown, 2014).

Some academics have also highlighted the failings of social workers in providing care or advocacy for many people with a disability. Oliver et al (2012: i), for example, note that:

Many thousands of disabled people continue to live in conditions that would not be tolerable to social workers or their managers who are charged with administering the welfare system...it looks increasingly likely that social work, due to its failure to recognise disabled people as [full] citizens, is moving closer to excluding itself from this area of practice.

Recent interviews with deaf and disabled adults who previously suffered abuse as children has underlined that in some cases formal care services were absent from their lives, or was wholly inappropriate (for example, Taylor et al, 2015). Non-verbal communication is often complex and difficult to translate, typically demanding a dynamic knowledge and skills-base, alongside sensitivity, patience and understanding. However, due to reduced access to specialist training and other resources, poor staff retention rates and a fragmentation of support services, social workers within local authorities may offer limited, or indeed poor provisions to disabled children (Morris, 2005; Young et al, 2009). Indeed, Mitchell et al, (2009) argue that the exclusion of disabled children from decision-making in social care processes echoes their exclusion from wider society. An example of this is reflected in their analysis of Serious Case Reviews which highlighted consistent failings in direct communication with children during assessments. Types of 'othering' and exclusion can further intensify in relation to other influences, for example once a child's minority ethnic status is taken into account.

Some limits to ethical codes in accommodating disability

Although offering moral frameworks that aspire towards personal autonomy, choice, empowerment or social justice, codes of ethics also have the potential to promote ‘groupthink’ and overreliance on institutionally-led imperatives (for example, Janis, 1982; Rossiter et al, 1996; Baines, 2013). Such claims are perhaps especially apt regarding overtly instrumental and bureaucratic forms of care management present within modern social work in various guises since the 1990s. Subsequent ethical implications include the potential institutional relegation of disabled children to objectified ‘service users’, or the provision of limited or inappropriate care based on elevated eligibility criteria for support. For example, Young et al’s (2009: 5-9) extensive survey of 57 local authorities providing statutory social work to deaf children, concluded that a lack of ‘specific attention to deaf children and families’ social care rights and needs’ were evident, alongside ‘poor recognition of need and provision of assessment’.

Explicit awareness of codes of ethics on behalf of practitioners for this research, however, tended to be restricted to vague recollection or general uncertainty. Codes were not consciously drawn upon and a workable sense of morality was identified as being influenced by following instinct or adhering to responsibilities to an employer. As two practitioners noted:

‘I’m vaguely aware of ethical codes [for social work] but have never consciously used these in my work... This is a very practical job with lots of challenges and time-scales to overcome’

‘You have to push to overcome any obstacles and rely upon gut instinct and your own beliefs. It’s never easy, and then there are all the responsibilities to your employer’

As well as comply with institutional or professionally-imposed objectives or discourses, not uncommon prejudices can subsequently influence perspectives in relation to disability. For example, similar to the ‘oldest old’, children with a learning disability are sometimes

assumed to carry uniform personalities and identities. Thomas (1999) notes a tendency among some professionals to prioritise the physical safety of disabled children, yet ignore the importance of a social life, friendships, psychological, emotional or identity-related support. This is despite such 'being' related factors remaining central to children's well-being and development. Within health or social care sectors, many such priorities are it seems now more likely to be neglected due to limited available time:

'To get the full picture, you need to take the time to know these children, more than just one snapshot assessment. To get a good understanding you cannot always gauge this from one visit'.

'My priority is gathering facts, and, if possible, talking to [the child] and ensuring they are safe and well. Even finding time to do this can be tricky...It's probably wrong but looking at friendships and other stuff is not my priority due to pressures such as meeting time-scales or getting the paperwork done'.

Principles such as utility or autonomy that commonly spring from ethical codes – and indeed other now conspicuous professional discourses such as those in relation to resilience or empowerment - did not always appear to lend themselves to the specifics or complexities of a non-verbal disability. For example, utilitarian-consequentialist ideals of 'social utility' may discriminate against both disability in principle and children, yet are paramount drivers within social policy and facets of ethical and professional codes (Rossiter et al, 1996; Hugman, 2005). They can look to maximise the benefits of a majority population, and such motivators were implicitly recognised by some of those interviewed. For example, one practitioner highlighted that local authorities invariably prioritised resources for children *without* a disability:

'There is not enough available, this is probably controversial to say, but the department tends to gear up the provisions for mainstream [non-disabled] children's

services and training reflects general issues. Disability teams get prioritised less, but children need to be more protected’.

Another practitioner was more explicit in her viewpoints about attitudes towards disability-related services:

‘It’s as if we’re at the bottom of the food chain, with anything related to mainstream services and safeguarding at the very top’.

Local authorities or senior managers who regulate funding for services and training may of course highlight their significantly reduced financial resources, which is typically out of their direct control. However, this appeared to generate little sympathy with many of those interviewed in justifying the relative neglect of a specific (non-mainstream) user group. Clearly, overreliance upon utilitarian thinking within welfare governance and policy has a detrimental impact upon groups including disabled people. For example, this may lead to too much emphasis being placed on ‘productivity’ or ‘economic viability’, utilitarian principles which persevere with often limited protection offered against how badly a person from a minority group can be treated (Kilner, 1996). In a similar vein, people who communicate non-verbally and have a learning disability may struggle to secure ‘universal rights’ in Kant’s terms. This includes that any capacity to count as ‘reasoning beings’ may be challenged consciously or otherwise from an overtly narrow professional perspective, such as by relying upon the opinions of parents. Deontological frameworks have also been linked to overt categorisation within professional labour processes and cultures (Wilmot, 1997), or can neglect the complexities of power and potential domination which can emerge within a professional/user dyad (Wilks, 2011). Such tensions can become much more potent in times of financial scarcity.

Whilst these principle-based frameworks carry influence in the defining of policy and governance they may be contested at the level of agency, such as during direct contact with

service users. In addition, alternative paradigms have emerged which challenge any reductive components or interpretations of utilitarianism or deontology. A notable example is the feminist-inspired ethics of care, and the gradual introduction of some of its ideals into formal codes of ethics alongside wider professional narratives. Among other examples, notable traits include its questioning of duty-based rules, autonomy, or any narrow focus placed on citizenship and individualism. Even here, nevertheless, in its attempts to prioritise gender inequalities, mutual support or community, there is a danger that female carers or parents might again be privileged above children who communicate non-verbally. This point was hinted at by one practitioner when she noted that:

‘Because of time and the need to gather so much information so quickly you often fall into the habit of relying upon the parent...They know so much about their children and, sadly, contact with the child is very brief or doesn’t really happen’

Other practitioners spoke about care givers and parents suggesting that it was best if their children were not present during assessments as ‘there’s no point’ or ‘she won’t understand what’s going on’. Meagher and Parton (2004) add that social workers are unlikely to always be faithful to the person-centred ideals of an ethics of care or virtue ethics when exposed for a prolonged period in welfare arenas dominated by bureaucracy, resource constraints and risk-averse cultures of practice.

Conclusions

A longer running debate about the relevance or otherwise of ethical codes continues. Banks (2004: 114-117), for example, has argued that there is ‘no doubt that codes of ethics are rather strange documents...which are sometimes ambiguous and contradictory’. Other critics maintain that they undermine ‘genuine ethical reflection and debate’, such as by promoting rule-following or the ideological indoctrination of overtly vague ‘blue skies’ ideals that are

unlikely to be taken seriously by world-weary practitioners (Petrie, 2009). This research, whilst small-scale, suggests that problems of *influence* and *application* of the more person-centred or constructive elements of codes can be especially pronounced in specific forms of social work which demand higher levels of inter-personal skills. More concerning however, remains the possibility that the aspirational certainties of principle-based frameworks may implicitly discriminate against some minority groups, such as due to an underplaying of specific needs. This may lead to an acceptance of institutional norms, and thereby help to validate disengaged practices. As Wilks (2011) notes, codes can also overstate the autonomy and discretion of professionals, and neglect the persistent effects of significant organisational restraints, or the impact of structural forms of disadvantage and power in relations with service users.

Such deficits or paradoxes are only likely to intensify further with the sustained influence of medical bioethics within social work. This particular principalist framework maintains an associated positivist stress upon users as 'subjects', as well as encouraging greater priority is given to objectivity, measurement, formality, evidence, and a concomitant narrow understanding of social relations and medically-framed 'needs'; with the latter often implying social dependency and physical decay (Estes et al, 1996; Zielinska, 2015). As one practitioner observed:

Everything seems so medically-focused now...although helpful to some kids it just all ignores so many other things which are part of childhood, like play, friendships, education and other stuff.

Such ongoing paradigm shifts within social work are likely to again only add further questioning of the limits of over-relying upon codes of ethics in education or practice, including in work with children who communicate non-verbally. Despite this, it is likely that

the use or otherwise of ethical codes can only be fully understood with reference to other influences, including the use of power or impact of discourse, social exclusion and political economy.

References

- Baines, D. (2013) 'Resistance in and outside the workplace: Ethical Practice and Managerialism in the Voluntary Sector' in Caney, M., Green, L. (eds.) *Practical Social Work Ethics: Complex Dilemmas in Applied Social Care* Farnham, Ashgate
- Banks, S. (2004) *Ethics, Accountability and the Social Professions* Basingstoke, Palgrave MacMillan
- Butler, I. (2002) 'Critical Commentary: A Code of Ethics for Social Work and Social Care Research', *British Journal of Social Work* 32 (2): 239–248.
- Congress, E. (2010) 'Codes of Ethics' in Gray, M., and Webb, S. (eds) *Ethics and Value Perspectives in Social Work* Basingstoke, Palgrave Macmillan
- Estes, C. L, Kelly, S.E, and Binney, E. (1996) 'Bioethics in a Disposable Society: Healthcare and the Intergenerational Stake' in Walters, J.W. (ed.) *Ethics and Ageing* University of Illinois, Chicago
- Hugman, R. (2005) *New Approaches for Ethics in the Caring Professions*. Basingstoke, Palgrave Macmillan.

Janis, I.L. (1982) *Groupthink: Psychological Studies of Policy Decisions and Fiascos* 2nd Ed New York, Houghton Mifflin

Kilner, J.L. (1996) 'Why now? The growing interest in limiting the lifesaving health care resources available to older people' in Walters, J.W. (ed.) *Choosing who's to Live: Ethics and Aging* Urbana and Chicago, University of Illinois Press

Meagher, G. and Parton, N. (2004) 'Modernising Social Work and the Ethics of Care', *Social Work and Society* 2(1): 10–27.

Morris, J. (2005). *Children on the edge of care: Human rights and the Children Act*. United Kingdom, London: Joseph Roundtree Foundation.

Miller, D., and Brown, J. (2014) *We have the right to be safe: Protecting disabled children from abuse* London, NSPCC

Mitchell, W., Franklin, A., Greco, V., & Bell, M. (2009). Working with children with learning disabilities/ or who communicate non-verbally, research experiences and their implications for social work education in increased participation and social inclusion. *Social Work Education*, 28(3), 309-324.

Petrie, S. (2009) 'Are the International and National Codes of Ethics for Social Work in the UK as Useful as a Chocolate Teapot?', *Journal of Social Work Values and Ethics* 6 (2).

Rossiter, A., Walsh-Bowers, R., & Prilleltensky, I. (1996) 'Learning from broken rules: Individualism, bureaucracy and ethics'. *Ethics and Behavior*, 6(4), 307-320.

Taylor, J., Cameron, A., Jones, C., Franklin, A., Stalker, K., and Fry, D. (2015) *Deaf and disabled children talking about child protection* Edinburgh, University of Edinburgh/NSPCC

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability* Open University Press

Oliver, M., Sapey, B., and Thomas, P. (2012) *Social Work with Disabled People* 4th Ed People Basingstoke, Palgrave MacMillan

Truman, C. (2003) 'Ethics and the Ruling Relations of Research Production' *Sociological Research Online*, vol. 8, no. 1, <http://www.socresonline.org.uk/8/1/truman.html> accessed: 3/11/2016

Wilks, T. (2011) 'Ethics and Power: A Discourse' in Okitikpi, T. (ed.) *Social Control and the Use of Power in Social Work with Children and Families* Lyme Regis, Russell House Publishing

Wilmot, S. (1997) *The Ethics of Community Care* London, Cassell

Young, A.M., Hunt, R., and Smith, C. (2009) *The impact of integrated Children's services on the scope, delivery and quality of social care services for deaf children and families* London, NCDS

Zielinska, A.C. (2015) 'Moral Principles and Ethics Committees: A Case against Bioethical Theories' *Ethics and Social Welfare* 9 (3): 269-279