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Mental health, human rights and social inclusion for adults and children

Introduction

In this article I discuss three recent papers. The first poses some questions about how different countries can address the human rights of people with disabilities (which includes people with mental health diagnoses) to be full participants in society. The second paper reports on participatory research looking at how children's rights can be better respected in relation to mental health diagnostic practices. The third paper reports on advocates in mental health, who support people detained or treated in England under the Mental Health Act, promoting their right to have a say in their treatment.

The rights of people with disabilities

Sherlaw and Hudebine (2015) suggest that the United Nations Convention on the Rights of Persons with Disabilities (2006) can be used by different nations to increase the social inclusion and participation of people with a range of disabilities. However, they also emphasize, as does the UN convention itself, that all interested groups need to be involved in the change process itself, and to have an equal voice. Sherlaw and Hudebine (2015) address the issue of how to measure progress on policies, and the outcome in different countries. To what extent do the policies really bring about change? In their ongoing process of setting up research in this area, Sherlaw and Hudebine (2015) highlight some difficulties in ensuring that all interested groups have a say in decisions about measuring whether countries are complying with the UN Convention (2006).

The need for research that includes all voices

Although there are ways of measuring whether policies fit the Convention, say Sherlaw and Hudebine (2015), there is a lack of ways of measuring how these policies affect people's lives. Devising an approach that is suitable in a given country and relevant to different groups of people, however, is not straightforward. For example, Sherlaw and Hudebine (2015) point out that change can be seen as a challenge to existing culture and practice. They also suggest that measuring the

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impact of policy changes cannot be done using experimental research, where people are randomly assigned to different conditions and measurements made before and after they experience these conditions. There is too much complexity, and wherever policy change happens there is a need to take account of local conditions, political tensions, and the people involved. Sherlaw and Hudebine (2015) suggest that 'realistic evaluation' is most suitable (Pawson and Tilley, 1997), because it is an approach that takes into account local context. Sherlaw and Hudebine (2015) also suggest that the research needs to be participatory and user-led. This will allow debate about sensitive issues rather than imposing decisions.

Sherlaw and Hudebine (2015) suggest that even where a country's policy allows for consultation with people with disabilities, this may not always be guaranteed. They discuss the case of France, where disability organisations are often run by people without disabilities and may also be providers of care. However, no distinction is made between these and user-led organisations. In addition, some groups that support those with disabilities have an agenda to protect and care rather than empower people. Some groups of people with disabilities are overlooked when different groups come together, such as people with learning disabilities. Sherlaw and Hudebine (2015) suggest that different groups should come together to have a stronger voice, but this introduces differences of agenda that may be hard to resolve.

There is also a need, say Sherlaw and Hudebine (2015), to ensure that disability groups include the voices of those without disabilities, as not doing so can reinforce the perception of the disability group as outsiders. Sherlaw and Hudebine (2015) also suggest that excluding the voices of those without disabilities contravenes the rights of the non-disabled for inclusion. Yet, together, disability groups and non-disabled people can potentially use and amend the UN Convention, co-construct the political agenda, and suggest areas for research and policy change.

Should difference be valued or reduced?

One tension within the concept of inclusion itself, suggest Sherlaw and Hudebine (2015), is where for some people it is an issue of recognising and valuing their difference, whereas for others, or at other times, it is an issue of reducing difference by creating the conditions where everyone has equal opportunity and participation. One group wishing their difference to be recognized and valued is that of deaf culture, suggest Sherlaw and Hudebine (2015).

In the case of cochlear implants, say Sherlaw and Hudebine (2015), deaf parents of deaf children may refuse to allow their children to be given implants that would enable them to hear. The parents value deaf culture and sign language as differences to be celebrated. Sherlaw and Hudebine (2015) suggest that there is a need to allow for these kinds of tensions, and to allow for both celebrating and reducing difference when deciding what measures to use in assessing the effect of policy change on people's lives. Participatory action research, say Sherlaw and Hudebine (2015), may ensure that all voices are heard as these decisions are made.

Do children have the right to be restless?

Sometimes disability may be assumed to exist in individuals where in fact the problem is in their surroundings. Helle-Valle, Binder and Stige (2015) ask whether children who are restless should continue to be treated as if they have a mental health problem, irrespective of their social environment and the way society understands children. They point out how prominent the idea of ADHD (attention deficit hyperactivity disorder) has become. Although they write from a Norwegian context, this seems to apply to many countries. They suggest that although ADHD as a description of child behaviour is easy to recognize, the reasons for the behaviour are less clear.

Why do so many children get a diagnosis of ADHD?

Helle-Valle et al. (2015) describe a pattern of problems with attention, hyperactivity, and impulsive actions, as set out by the American Psychiatric Association (2013). They note that it is the most common of all psychiatric diagnoses given to children around the world, at over 5% (1 in 20).

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Although tests find specific difficulties in children with ADHD, children with other diagnoses can have the same difficulties, so there is no evidence of a specific brain disorder.

There have been increases in the prescription of stimulants, mainly Ritalin, in a number of countries, say Helle-Valle et al. (2015), especially for boys. Children, when asked, are less keen on medication than their parents, with some wanting to stop taking it, although some say it helps them conform to expectations.

Helle-Valle et al. (2015) draw on the work of Singh (2004) to suggest that in today's society, there are cultural ideals of motherhood that leave mothers vulnerable to self-blame and blame by others if their children misbehave. The ADHD diagnosis can be seen as a way of deflecting this blame, by placing the problem in the child. Ritalin is seen by both parents as easing the mother's anxiety.

What causes children to be restless?

Helle-Valle et al. (2015) point out that treatment with stimulants does not predict outcome 6-8 years later, and social deprivation is strongly linked to children getting an ADHD diagnosis. Helle-Valle et al. (2015) refer to two studies that suggest how parents living in deprived conditions (and therefore under stress), have less good relationships with their children, who in turn are more likely to have behavioural problems and get a diagnosis of ADHD. Other research, say Helle-Valle et al. (2015), suggests that abuse and violence in families leads to children finding it difficult to control their behaviour, which may explain why ADHD is a common diagnosis in families where violence or child abuse is identified. In fact, Helle-Valle et al. (2015) point out that maltreatment of children is an urgent problem. They express puzzlement that it is not more prominent in discussion and research on children's restlessness.

What were the aims of the study on children's restlessness?

The aims of Helle-Valle et al. (2015) for their study were to explore how parents and professionals understand children's restlessness. They used co-operative enquiry as their research

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method. This is a form of action research, that is, it had an aim of bringing about a change. The change in this research was in the participants' understanding of children's restlessness. The research was co-operative in enabling different viewpoints to be shared through a discussion group made up of a range of professionals and including parents. The parents of 13 five-year-old children taking part in a community music therapy project were invited to be part of the co-operative enquiry group, and three agreed to take part, all fathers. One father dropped out after the first meeting. Professionals from local organisations that referred children for treatment were also invited. The seven professionals, all women, came from teaching, the play group, music therapy, psychology, child welfare, child and adolescent psychiatry, and primary care.

What happened in the study on children's restlessness?

There were four meetings over seven months, and in the first one the two facilitators answered participants' questions about ADHD, including explaining research findings and different ways of understanding it. Helle-Valle et al. (2015) note that the fathers tended to ask questions and the professionals answered them. Fathers were curious about why the ADHD diagnosis is used so much.

The discussions were audio-recorded and made anonymous. Thematic analysis was used to summarise the themes discussed. The facilitators sent a summary of the discussion to all participants after each group. Members could comment on a first draft of the study report, and these comments influenced the final version. Although themes came from the discussion, Helle-Valle et al. (2015) grouped them according to level in their theoretical framework: (1) the child, (2) dyad, group or family, and (3) community.

The child – creative or traumatised, but definitely misunderstood

At the level of the child, children were often seen as the problem. However, they were also seen as perhaps having a creative personality. A diagnosis of ADHD might, in this case, obscure their special abilities. The GP said that as a result of the discussion group, referrals for ADHD were going

down, and there was more co-operation between agencies. Parents were more likely to be asked about the child's resources and to be observed during consultations to give some context, and this observation to be reported in referral letters.

There was a view that children are more demanding than in the past, creating more problems. However, at the end of the first meeting one father suggested looking at how adults contribute to children's behaviour.

The group discussed the research that links children's behaviour problems to their experience of trauma. Members wondered if adults were avoiding their responsibilities. It seemed difficult for adults to take action when there was threat to children from domestic violence. There was also a suggestion that perhaps adults need a better understanding of children.

Dyad, group and family – perhaps adults do not have time and resources for their children

Group members felt that children must be allowed to express their needs but adults must provide guidance. Children could show signs of difficulty or distress either by withdrawing or behaving restlessly, and both could be seen as communication. In a play group with 16-18 children, different children have different needs, and there should be at least four adults. Fathers were clear that they wanted their children to behave well towards others.

Discussion group members talked about mothers being less confident today about parenting, and about working parents' tiredness making them less able to cope. Perhaps getting a diagnosis of ADHD for their children enabled parents to avoid having to deal with their own problems. Children may be affected by a tense atmosphere in the home. Perhaps parents could use more praise and positivity in their parenting strategies, and learn ways to help their children control themselves. Professionals felt they should not shy away from seeing this as parents' responsibility.

Community – not well organised to support children and their families

Some discussion group members wondered if the level of support for some families was adequate. The GP told a story of a mother left unsupported when returning home from a hospital

admission with a mental health diagnosis. She had a baby and a small girl, and was struggling. She was advised to refer the girl for problem behaviour, even though it was understandable in the circumstances. The mother did not get the support that should have been available because a professional had been on holiday. The group felt that although the diagnosis of ADHD and medication seemed like a quick fix, it was actually better in the long run if professionals could prioritise working with parents to support the family.

The discussion group talked about a lack of resources, knowledge and competence among adults that left children or their families poorly supported. Children were often encouraged to play sport or go to summer camp more for the benefit of tired adults than for the children's own benefit. Play group buildings might not be best designed for promoting children's development. Parents might be over-optimistic about children not hearing them argue after children's bed-time. Group members wondered if adults make sufficient use of children's own creativity to help resolve problems. Music therapy was mentioned as one approach to children's restlessness.

Ways forward for restless children

Discussion group members were fairly clear by the end that ADHD was not the best way to understand children. There was concern that the ADHD diagnosis obscured a host of problems in the child's home and the community. Participants all wanted to improve children's situation, and saw children's restlessness as a shared problem. This common interest on behalf of children could be seen, suggest Helle-Valle et al. (2015), as 'solidarity', a concept that appears in the United Nations Declaration on the Rights of the Child (United Nations, 1989).

There seemed to be a case for greater integration between research on ADHD and research on child maltreatment. In addition the child's own perspective needed to be heard, but a diagnosis of ADHD made this less likely to happen. It was important to always consider that children's behaviour is affected by what is happening around them, either through insufficient stimulation leading to boredom, or over-stimulation or stress making them feel unsafe, which would require

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support to calm down. A diagnosis of ADHD should not be used to help adults avoid their responsibilities towards children.

It was unfortunate that no mothers took part in the study, and only two fathers. Perhaps the subject of study played into the parents' feelings that society tends to blame them for their children's restlessness. It is possible that mothers may have felt blamed when professionals and fathers talked about parents needing to take more responsibility for their children's learning to control their own behaviour. However, the discussion also may have enabled them to develop a broader view of the issues, and voice the need for more understanding of the position of families expected to be above all economically active, despite sacrifices for family life.

The rights of people detained under the mental health act

Newbigging, Ridley, McKeown, Machin and Poursanidou (2015) highlight state powers to detain people with mental health diagnoses, and also the English law allowing compulsory treatment in the community. Newbigging et al. (2015) remind us that the World Health Organisation (2003), called for people with mental health problems to be supported by advocates to protect their rights. In relation to the imbalance of power when someone is detained, say Newbigging et al. (2015), advocates help ensure that service users have a say in decisions about their care. Advocates have been available in England since 2007 but their services had not been evaluated systematically and nationally.

Newbigging et al. (2015, p. 315) needed to find out what good advocacy services looked like in the eyes of service users, those who commission them, and those who provide them, and how good the advocacy services actually were, across the range of service users and in different places.

How did the authors find out what quality means for advocacy services?

To carry out their first aim, Newbigging et al. (2015) sought the views of 75 participants through focus groups held in London and the major regions of England, and including service users, carers, advocates, mental health professionals and one commissioner. They found commissioners

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difficult to recruit at the time (late 2010). The views of these 75 participants led to a list of ways in which the quality of advocacy services could be assessed, such as how available it was, its independence, the range of needs it met, and the effect it had for people who used it.

How did the authors find out how good advocacy services were?

For the second study aim, Newbigging et al. (2015) used a systematic case study approach (Yin, 2008) to ensure that they collected the right information from a range of mental health services in England. Locations covered inner city, urban, suburban and rural areas, and both medium and low secure services. Information was collected from questionnaire responses, service documents, interviews with 20-25 people at each place, and case notes for 20 service users who gave consent. A total of 214 people were interviewed. Ten of the 13-member research team were service users themselves. The number of service users interviewed was 90, of whom 75 had been sectioned more than once, and 61 had used an independent advocate.

Were advocacy services protecting people's rights?

Service users who were interviewed spoke of the over-use of physical force to detain them, or having their views on what would help their recovery dismissed when in hospital and being kept in too long. Those who had not experienced advocacy felt it would have helped. The top two reasons service users who had referred themselves to advocacy gave for doing so were to be heard and to have the section removed.

Newbigging et al. (2015) found that access for those who qualified for advocacy was very low in an inner city location (19%), and much higher in a secure facility (92%), perhaps because there was a routine process and less patient turnover in the facility. People on community treatment orders tended not to have good access (from 5% to 55% across different places). Lower access was seen in women and those from Black and minority ethnic communities, for children and young people, and for older people with dementia.

Advocates had widely different sized caseloads, from 8 to 55, and there appeared to be no systematic assessment of what was needed when services were commissioned. Service users who qualified but did not have advocacy tended to lack information about it, whereas professionals thought they chose not to have it. Professionals working in secure facilities mostly knew they should provide advocacy, whereas those in other places were less knowledgeable. Some staff thought it was only needed where a service user lacked capacity or had no family. There was a lack of training. Some staff felt that advocates did not visit wards often enough, but advocates spoke of limited resources. Carers seemed not to know about advocacy services.

Service users who had used advocacy generally found it helpful, but advocates did not always understand issues for minority groups, such as racism. People with learning disabilities or hearing problems did not usually have access to advocates with relevant training. Service users were not usually involved in service planning or evaluation. Despite a lack of diversity among advocates, service users appreciated their ability to support them. As advocates were rarely trained to work with people lacking capacity, older people with dementia were poorly served. Some advocates felt they were being pulled into legal areas because of reduced provision of legal aid.

Service users felt that advocates were vital, and indeed could be life-changing. Even without a specific outcome, the advocate could lead to the service user feeling that they were treated more like a person rather than “a bit of dirt under their feet” (Newbigging et al., 2015, p. 321). Advocacy let more light into the institution, and staff behaved better as a result. Only a few service users felt that the advocate had maintained an unsatisfactory situation. Professionals were varied in how well they understood and accepted the advocate role, with some having difficulty when they felt their clinical judgment was challenged, while others accepted different perspectives.

Newbigging et al. (2015) suggest that their findings point to several groups being disadvantaged in having less access to advocacy than others: those from Black and ethnic minority groups, older people with dementia, people with learning disabilities or sensory impairments, those

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on community treatment orders and young people. They suggest advocacy should be offered to all who qualify rather than only on request, and to provide it to all inpatients, along with information. More collaboration is needed with local community groups, and professionals need training to see the importance of service user empowerment.

Conclusions

The UN Convention on the rights of people with disabilities champions social inclusion for people with mental health diagnoses as well as others. However, they must be involved in both the process of measuring whether countries change their policies, and whether new policies lead to improvements in their lives. Otherwise claims may be made about improvements for them that ignore ongoing discrimination and exclusion. Children's rights are protected by the UN Convention on the rights of the child (United Nations Organisation, 1989). The misuse of diagnosis to label restless children as mentally ill is unacceptable when the adults in their lives are stressed and unsupported. Amid claims that children are more demanding than ever, they are actually silenced by diagnosis. This absolves their mothers whom society is quick to blame when things go wrong, but it is time we moved beyond the blame culture and saw the bigger picture: We must acknowledge the relentless pressure on parents to be constantly economically active and the devaluing of childcare as a relatively unimportant activity. Finally, where adults are detained because they are seen as a threat to themselves or others, they must be afforded the right to have compulsory detention lifted at the earliest opportunity, and not to be viewed as incompetent to have a say in their care merely on the basis of having been sectioned.

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