

Cognitive, Behavioural and Emotional Benefits of Deinstitutionalisation for Children with Disabilities: A Comparative Study of the United Kingdom and India

Institutionalised Children Explorations
and Beyond

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Abstract

Research states that institutionalisation often results in negative outcomes for children's mental, physical and emotional health and behaviour. Alternatively, deinstitutionalisation can buffer this negative impact across countries and cultures. However, these results have been inadequately replicated with children having disabilities, who are at heightened risk of negative psychosocial outcomes of institutionalisation. Owing to the large number of children with disabilities in institutional care and this seems unrepresentative and undesirable. In the current article, the cognitive, emotional, mental health, and behavioural benefits of deinstitutionalisation for children with varied disabilities in India and UK are discussed. For this, the researcher's compilation of observational data and personal reflections from 4.5 years of practical work with deinstitutionalised children with disabilities is used. Further, interview extracts and reflections from children and their adoptive/foster carers post deinstitutionalisation are included. With this, an attempt is made to advance how and why deinstitutionalisation is beneficial for children with disabilities.

Key words

Deinstitutionalisation, mental health, cognition, behaviour, cultural comparison

Institutionalisation refers to a large or small organisation within which individuals are compelled to live together in isolation from the mainstream community (UNICEF, 2014). These organisations display characteristics typical of institutional

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cultures like depersonalisation, a rigidity of routine, block treatment, social distance, dependence and lack of accountability (Gudbrandsson, 2004). Since approximately 8–9 million children with disabilities are institutionalised globally, they form an overwhelmingly large section of individuals living under the institutional care (Browne, Hamilton-Giacritsis, Johnson, & Chou, 2005).

The Human Rights Watch (2017) reports that children with disabilities living in institutionalised care are subjected to involuntary invasive medical procedures (such as Electro Convulsive Therapy), neglect, overcrowding, denial of education, solitary confinement, denial to keep regular contact with family members and sexual, physical, verbal and mental abuse. Subsequently, they face higher chances of having poor health, physical underdevelopment, motor skill delays, hearing and vision problems and reduced cognitive and social abilities (European Commission, 2009). Further, a lack of autonomy, self-worth and integrity, whilst living in institutional care, is correlated with high susceptibility to mental disorders, heightened anxiety, fear of being abandoned, fear of being alone and a pervasive difficulty in distinguishing right from wrong (Rutter, 1998).

A meta-analysis of existing studies indicates that children with disabilities are 3.7 times more likely to be victims of any sort of violence than other children, 3.6 times more likely to be victims of physical violence and 2.9 times more likely to be victims of sexual violence (Human Rights Watch, 2014). The experience of the early institutionalisation continues to harm children with disabilities as they grow into adults (Stativa, 2000). Brown (2002) found that severely reduced life chances for adults who had spent their childhoods in institutions: 20 per cent had a criminal record, 14 per cent ended up in prostitution and 10 per cent committed suicide.

Alternatively, observational studies have reported that deinstitutionalisation (through a return to the family home, foster carers, adoption, etc.) has resulted in physical, intellectual, emotional and social development among children with disabilities (Jones, 2012). Studies show that children who were moved from an institution into a family-based environment demonstrated improved intellectual functioning, attachment patterns and reduced emotional withdrawal (Human Rights Watch, 2013).

While working with children with disabilities, living in several residential homes, institutes for the disabled, healing centres and psychiatric wards, both in India and the UK, it was evident through personal observations that these children aspire and yearn to live a normal life in the community. Further, it was noted that foster carers, adoptive parents, institutional authorities and children (with disabilities) themselves report significant positive physical, emotional, social and behavioural changes, post deinstitutionalisation. In the following sections, some anecdotal accounts, which summarise the benefits of deinstitutionalisation, are described.

Cognitive Improvement Post Deinstitutionalisation

Research suggests that prolonged institutionalisation of disabled children impairs brain development, eventually leading to severe cognitive delays and possible intellectual disabilities (Sullivan & Knutson, 2000).

Whilst working with children, both in India and the UK, it was observed that institutionalisation (in residential homes, special schools for the disabled and orphanages) for six months or more led to a significant decline in cognitive abilities. For instance, in most of the institutes, it was found that the general intelligence and working memory of children was elicited through standardised intelligence tests (Wechsler's Intelligence Scales-Children) at the onset, that is, when children entered the institute and then periodically, that is, after every two years of the child's stay. It was observed that children's scores on these cognitive measures declined progressively (when compared with their own baseline scores on entry in the institutes), as they spent more time under institutional care. Further, it was noted that children often reported a steady decline in creative inclinations, as they spent increasing time under institutional care. For instance, many children reported that when they were in the community, they would engage in art, craft, writing etc., but they did not desire to indulge in creative activities ever since being in the institutional care. Institutionalisation further seemed to constrain engagement with and aspirations for a brighter future.

Deinstitutionalisation (through adoption or foster carers) potentially leads to an improvement in children's cognitive abilities (Crosse, Kaye, & Ratnofsky, 1993). Through improvements observed in children's academic scores and creativity (asserted through personal observations and foster carer/adoptive parent report), post deinstitutionalisation, which had increased significantly, postulated that increased motivation coupled with adult attention and increased cognitive skill contributed to this improvement. Perhaps, a general sense of despondency along with reduced stimulation contributes to reduced cognitive abilities in children with disabilities under institutional care.

Behavioural Changes

Blackburn, Spencer, and Read (2010) suggest that 6 to 13-year-old children, living under institutional care, display more aggressive behaviours, greater defiance and are more likely to indulge in delinquency, stealing, lying and hyperactivity in comparison to children growing in family care.

In interacting with children in institutional care, it was observed that aversive behaviours such as delinquency, aggression, theft, inflicting injury on individuals or animals, and causing damage to property or objects were more common among institutionalised children in India in comparison to the UK. However, negative isolating behaviours such as withdrawal from social activities, extreme inactivity and prolonged reluctance to communicate was more commonly observed among children in the UK. It is supposed that cultural factors can possibly influence this difference. Through anecdotal interactions with institution staff and legal authorities in both the countries, it was found that this externalising behaviour is more severely punished and is increasingly amenable to legal repercussions in the UK, whereas these behaviours are sometimes overlooked in India. Additionally, it was observed that isolating behaviours are not considered as aversive or significantly noteworthy

in India and can subsequently remain unobvious; however, in the UK, silence gets noticed more quickly and is viewed as comparatively more unfavourable.

Conversely, it was seen that both externalising and isolating behaviours of children declined to eventually disappear post deinstitutionalisation. Post-adoption parents of the previously aggressive and delinquent children (both in India and the UK) have reported a marked reduction in anger and destructive behaviours (e.g., throwing objects and stealing) 4–6 months after adoption. Similarly, fostered/adoptive parents report an increased frequency of positive social behaviours (e.g., sharing, group-play) in these children, approximately after one year. However, late adoption/fostering (after age 15) does not seem to demonstrate such obvious positive changes in children's behaviour (Berens & Nelson, 2015). Hence, through personal observations, early deinstitutionalisation reflects greater positive effects on children's behaviour and developmental outcomes.

Reduction in Negative Emotions

Institutionalisation often results in feelings of despondency, worthlessness, abandonment, neglect and general pervasive despair (Spreat, Conroy, & Fullerton, 2004).

In their interactions, children with disabilities in the institutional care of residential homes and special schools (India and the UK) reported heightened anxiety and fear. They report that they are 'unwanted', 'god's unfavored children' and 'worthy of being at the peripherals of society' (L'Arche Canada, 2014).

Child A, a 13-year-old living in a special school for the Visually Impaired in India, shared that 'Sometimes I hate myself, and on other occasions, I hate my parents who did not throw me away soon after I was born'. Another child B, with Cerebral Palsy in the UK (14-year-old), living in a residential home, accounted that 'I do not see any point to life, one day flows into another, but the days never change. It all seems the same, no growth whatsoever'.

Institutionalised children also report greater mood fluctuations with moment-to-moment shift in emotions (ranging happy, sad, fearful, optimistic and hopeless) in as short a duration as 10 minutes. However, post deinstitutionalisation, children with disabilities seem to display greater emotional stability, increased life satisfaction and reduced feelings of dejection and despondency (European Commission, 2010). Child A (as mentioned earlier) post deinstitutionalisation for one year stated that;

I used to be so sad before finding my new parents. Life had no meaning back then. Now, I have a place I can call home, I can aspire for a better tomorrow and in the darkness, caused by blindness, I hope to develop a vision.

Child B too, post fostering for six months reported: 'I am far happier; truly, cuddling with an adult is bliss'. Further, the adoptive parents and foster carers of both these children, and several similar other children, report a general elevation of mood, behaviour and social interactions post deinstitutionalisation in the

children. Hence, it may be derived that deinstitutionalisation plays a crucial role in regulating negative emotions and increasing life satisfaction in children with disabilities.

Alleviation of Psychopathological Symptoms

Researchers claim that prolonged institutionalisation can lead to externalising disorders, such as Attention Deficit Hyperactivity Disorder, Conduct Oppositional Defiant Disorders and internalising disorders, such as Anxiety Disorders and clinical depression, along with attachment difficulties (Soper, Ward, Holmes, & Olsen, 2008). The effects of these are considered hard to alleviate.

It was observed that internalising disorders, such as depression, were increasingly found in institutionalised children in the UK, whereas externalising disorders, such as Conduct Disorders, were more prevalent among Indian children. Conversely, a reduction in psychopathological symptoms post deinstitutionalisation was noted. This outcome was more pronounced in India, wherein possibly externalising behaviours reduced after receiving the attention and compassion of caring adoptive parents. However, the reduction in internalising symptoms were less obvious. It took longer, perhaps more than a year, for these symptoms to subside. Hence, potentially, institutionalisation leaves a lasting effect on children's psychological health.

In conclusion, through working with institutionalised children for over four years in two different countries, and consequently varying cultures, it is posited that institutional care leaves an indelible mark on the mental health of children with disabilities. However, subsequent deinstitutionalisation can help to counter the social, emotional, behavioural and cognitive damage. Therefore, deinstitutionalisation seems beneficial for increasing the overall social and mental well-being of children. Future research must attempt to compare its effects in diverse cultures and different countries to confirm its universal benefits.

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