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Moving Out: The Impact of Deinstitutionalisation on Salient Affective Variables for People with Mild Intellectual Disabilities [R]

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This study examined the affective functioning of people with mild intellectual disabilities through examining salient variables that impact of people with disabilities who have been deinstitutionalised. Its primary purpose was to extend previous research by incorporating adaptive behaviour, quality of life, in combination with multidimensional self-concept, self-esteem and locus of control, in a longitudinal/comparison design. The study utilised a longitudinal/comparison group design. The results showed that the people who were deinstitutionalised benefited in some aspects of multi-dimensional self-concept, some subscales of quality of life, and three out of five factors of adaptive behaviour. The findings have important implications for current theory of the self-concept for people with intellectual disabilities, the provision of programmes and techniques to improve self-concept, hence the social integration of people who have been deinstitutionalised.

Although there is now wide recognition of the rights of people with intellectual disabilities to be fully integrated into the community, there have been few attempts to examine the impact of deinstitutionalisation on the affective development and social competence of people with mild intellectual disabilities. Although the consensus both here and overseas is that the physical placement of people with intellectual disabilities away from institutions and into the community has been largely beneficial, there is still an acknowledgement that social integration has not been achieved and that many people continue to lead lonely, isolated and socially restricted lives. Therefore, despite the acceptance for many years of the principles of normalisation, social role valorisation and deinstitutionalisation, there is some dissatisfaction with the outcomes, particularly in the area of social integration.

Historically, the principles of normalisation combined with the Civil Rights movement of the 1960s led to the deinstitutionalisation movement. One consequence of this movement has been to revolutionise service provision for people with intellectual disabilities. This has been reflected in the considerable effort in many Western countries to relocate persons with intellectual disabilities from large congregate institutions to smaller community-based facilities or into independent living environments. For example, in the USA over the past three decades, the significant reduction in the number of people with an intellectual disability living in large institutions has been associated with a corresponding growth in community-based living arrangements (Larson & Lakin, 1989). These trends have also been observed in the United Kingdom and many other European countries (Emerson & Hatton, 1996). In Australia, the deinstitutionalisation of people with intellectual disabilities and the development of community-based services began later than elsewhere in the world and progressed more slowly than in either the UK or USA (Young, Sigafos, Suttie, Ashman & Grevell, 1998). In fact, the first integrative review for deinstitutionalisation using only Australian studies was published in 1998 (Young et al., 1998). However, most Australian states have now embraced the philosophies of normalisation, social role valorisation and deinstitutionalisation and are currently reviewing the provision of residential services for people with intellectual disabilities. One of the goals of deinstitutionalisation, that of physical placement in the community, has been achieved. However, although it is practice now to house people with intellectual disabilities within the community, the second goal of deinstitutionalisation, that of social integration, still needs to be accomplished.

Self-concept, self-esteem and locus of control have been considered to be important variables of psychological well-being. For people with mild intellectual disabilities a strong relation exists between self-concept and acceptance of disability (Li & Moore, 1998) and low self-esteem is associated with impoverished social relationships. Self-identity, confidence and feelings of worth, influence the way an individual interacts with the environment. Participating fully in society and being accepted by others requires a positive self-concept. Therefore, if people with disabilities are to achieve social integration it is imperative that there is a better understanding about the impact that deinstitutionalisation may have on their self concept, self-esteem and locus of control. Even though self-concept, self-esteem and locus of control are so crucial to the implementation of these policies they have largely been ignored, with few studies, apart from the personal control paradigm emanating from Wehmeyer and his co-workers, (Wehmeyer and Bolding, 1999) going beyond the measures provided by the relevant subscales of the Adaptive Behaviour Scale (Mathias, 1990), or Quality of Life domains (Brown & Goldenberg, 1993).

More generally, research has found that when people with intellectual disabilities are moved from institutions into smaller community-based services, positive outcomes have been recorded (Emerson & Hatton, 1996; Larson & Lakin, 1989; Young et al., 1998). However, positive outcomes have not been always followed deinstitutionalisation. It is now being recognised that mere placement in the community is not always sufficient (Jahoda, Cattermole and Markova, 1991). Individual characteristics of clients and the nature of the services received in the community may be very significant to maintaining normalisation and social role valorisation. One of the areas that has consistently been found to have an impact

on community-based living is the social competencies and affective functioning of people with intellectual disability (Ralph & Usher, 1995). Given the recognised importance, it is surprising that these have not been the focus of more research in either the Australian or overseas context.

Therefore the aim of this study was to assess the impact of deinstitutionalisation using a longitudinal/comparison group design that examines the impact of deinstitutionalisation across the traditional areas of quality of life and adaptive behavior, and the more salient variables which have been shown to have an important impact on social competencies in the regular population (multi-dimensional self-concept, global self-esteem and locus of control).

Methodology

Instrumentation

To measure the impact of deinstitutionalisation on affective variables and multi-dimensional quality of life and adaptive behaviour. Repeated measure analysis of variance was used to investigate whether there would be any change in multi-dimensional self-concept facets as measured by the Self-Description Questionnaire III (Marsh, 1989) and global self-esteem as measured by the Coopersmith Self-Esteem Inventory-Adult Form (Short Version) (Coopersmith, 1981), to determine whether there would be a shift to internality for locus of control, the Adult Nowicki-Strickland Internal-External Locus of Control Scale (Nowicki & Duke, 1974) was used. To determine whether there would be increases in some of the objective and subjective subscales of multi-dimensional quality of life for the Movers the ComQol-15 (5th Edition)(Cummins, 1997) was used. Finally, for the Movers, whether there would be increases in Personal Self-sufficiency, Community Self-sufficiency, Personal-Social Responsibility factors, and no changes in Social (Maladaptive) behaviour, and Personal (Maladaptive) behaviour adaptive behaviour was measured by the AAMD-Adaptive Behaviour Scale (Nihira, Foster, Shellhaas and Leland, 1974).

Research Design

A longitudinal and comparison group design was employed. All participants were administered the battery of measures at Time1 when they were all living in an institutional setting; and again at Time2, 30 months after the Movers moved to living independently. The comparison group (Stayers) remained living in an institution.

Participants

There were two groups of participants for this study:

Movers - 25 adults who all resided in a residential service established for people with intellectual disabilities, age ranged from 32 to 65 (mean 47.9 ± 9.7 years)

Stayers - a comparison group of 27 residents with intellectual disabilities who were not moving to the community and who were living in a different residential facility, age ranged from 18 to 55 (mean 36.1 ± 8.1 years).

Statistical Analysis

Data were analysed using SPSS for Windows and were analysed using repeated measures where time (two occasions) and two groups (Movers vs. Stayers) were the independent variables. The statistic of interest was a significant Group x Time interaction, indicating that change over time for one group differed from change over time for the other group. To determine the nature of the interactions post hoc analysis (simple main effects) were used to test a priori predictions.

Results

Multidimensional Self-Concept

The results demonstrate that there were significant interaction differences for the scores of the Movers in comparison to the Stayers for Academic ($F = 4.33, p < .05$) and Physical Appearance ($F = 4.97, p < .01$) and Emotion ($F = 4.14, p < .05$) subscales of the SDQ-III, whereby the Movers increased after moving to the community. These results show that the Physical Appearance Self-concept, Academic Self-concept and Emotion Self-concept showed significant increases for the Movers, over the Stayers.

A majority of the subscales showed no significant changes but there were no results on the SDQ-III suggesting that the Stayers increased in multi-dimensional self-concept facets more than the Movers. This tends to lend support to the conclusion that integration into the community did not lead to a decrease in self-concept, and there was an increase in multi-dimensional self-concept in some areas conceptually related to deinstitutionalisation.

Global Self-esteem

The repeated measures analysis of variance revealed no significant main effect for group or time and no interaction effect. These results indicate that no change was observed in global self-esteem for adults with mild intellectual disability who have been deinstitutionalised over 30 months in comparison to adults with intellectual disability who have not been deinstitutionalised. However, moving to the community again was also not related to any decrease in global self-esteem for the Movers.

Locus of Control

The repeated measures analysis of variance revealed no significant main effect for group or time and no interaction effect. The results indicate that the Movers and the Stayers remained highly external in their locus of control throughout the period of this study. These results are similar to the results found for the population of people with intellectual disabilities across the lifespan.

Quality of Life

Significant interaction effects were found for the Objective Community ($F = 4.01, p < .05$) and Objective Material ($F = 25.42, p < .01$) domains, and for the Subjective Material ($F = 5.98, p < .05$) and Subjective Safety ($F = 4.41, p < .05$) domains over 30 months favouring Movers over Stayers.

There were no significant main or interaction effects present for the Objective Health, Objective Productivity, Objective Intimacy, Objective Safety, Objective Emotion, Subjective Health, Subjective Productivity, Subjective Community or Subjective Emotion scales.

The move to the community for the Movers resulted in significant increases in both objective and subjective quality of life. The two objective scales that showed the significant results, Objective Community and Objective Material were the ones hypothesised to have the closest relation to deinstitutionalisation. The Subjective subscales that showed significant increases for the Movers, Subjective Material and Subjective Safety, were also closely related to successful deinstitutionalisation. One of the reasons given for not placing people with intellectual disabilities in the community is that they will feel more vulnerable and less safe.

Although the majority of the subscales did not show any significant results, there were no subscales where the Stayers improved over the Movers. Therefore, the move to the community did not lead to a decrease in quality of life in any area and led to increases in quality of life in conceptually interpretable areas in both objective and subjective subscales.

Adaptive Behaviour

The move to the community for the Movers was associated with significant interactions effects in Community Self-sufficiency and Personal Social Responsibility. Socially challenging behaviour decreased for the Movers. Personal (Challenging) Behaviour did not increase for the Movers after deinstitutionalisation. Overall the results indicated that the move to the community for the Movers was associated with positive improvement in Community Self-sufficiency ($F = 9.95, p < .01$) and Personal Social Responsibility ($F = 11.28, p < .01$). The lack of significant interaction for Personal Self-sufficiency (Factor 1) could reflect a ceiling effect as the participants in both groups scored at very high levels in the Subscales that loaded heavily onto this Factor. Social (Challenging) Behaviour (Factor 4) decreased significantly ($F = 4.03, p < .05$) for the Movers over 30 months in the community but not for the Stayers and there was no increase in Personal (Challenging) Behaviour (Factor 5) for either group.

These results, then, support the contention that deinstitutionalisation will have a positive impact on adaptive behaviour. Significant improvements for the Movers were found in three of the five factors, Community Self-sufficiency, Personal-Social Responsibility and Social (Challenging) Behaviour. Also Personal (Challenging) Behaviour did not increase after deinstitutionalisation. Again, as with all of the other measures there was no decrease in adaptive behaviour for the Movers, relative to the Stayers. Overall the finding for most of the constructs were stable for the stayers as would be predicted for a comparison group that did not receive any type of intervention.

Discussion

The central finding of this study was that there was clear support for deinstitutionalisation for adults with mild intellectual disability and that there was no advantage gained by the adults remaining in the institution. What differences there were between the Movers and the Stayers were always in favour of the Movers. At no time did the group that was not deinstitutionalised show any changes that would suggest that they benefited from remaining in the institutionalised setting and the results do not report any negative impact (changes) for the group that was deinstitutionalised. The results of this investigation support the findings of previous research that has shown the benefits to people with intellectual disabilities of

the move from institutions to live independently in the community (Larson & Lakin, 1989; Kim, Larson, & Lakin, 2001; Felce & Perry, 1996).

Each of the variables examined revealed a different aspect of the complex picture of the effects of deinstitutionalisation, and, as such, the examination of this range of affective variables strengthens the validity of the conclusions that there was a positive impact with deinstitutionalisation. This positive impact was found for facets of multidimensional self-concept, quality of life and adaptive behaviour.

Multi-dimensional Self-concept and Global Self-esteem

This study was the first to investigate the impact of deinstitutionalisation on multi-dimensional self-concept facets. The results clearly favoured the Movers over the Stayers on the dimensions of Academic, Physical Appearance and Emotional self-concept. There were also large increases over time for the Movers in Physical Ability and Maths self-concept. The Physical Ability dimension is conceptually closely related to successful deinstitutionalisation and successful integration in the community (Kim et al., 2001) because of a person's perceived ability to achieve tasks and to move around the community. The changes in the Maths dimension, although a little unexpected, could be accounted for by the successful use of banking facilities, shopping independently and handling money. Other studies have reported changes in academic ability as a result of deinstitutionalisation (Lynch, Kellow & Wilson, 1997). It was, however, also encouraging to see that Physical Appearance and Emotional self-concept also improved for the Movers.

This study used the SDQ-III to identify whether multi-dimensional instrumentation had greater explanatory power than the unidimensional global self-esteem measures. The SDQ-III showed some significant changes over 30 months of the research period but the Coopersmith SEI did not reveal any differences. The results of this research are encouraging although further research using the SDQ-III is needed with larger populations. The fact that not all of the subscales showed differences is similar to the findings of other studies. Often children and adults with different disabilities have been shown to score lower on self-concept scales only on those dimensions directly affected by their disability (Chapman, 1988, Johnston, 2001). This might explain the change in Academic and Maths subscales, as these are the two scales most closely aligned to intellectual disabilities. The self-concept of Physical Ability subscale results were also analysed as physical ability in previous research has had such a strong relation with successful deinstitutionalisation. Physical Ability self-concept improved over the 30 months for both groups, but much more for the Movers. The Maths subscale also improved significantly as well. The Physical Ability self-concept score changes and Maths self-concept changes must be interpreted cautiously, as the interactions were not significant, however, improvements over time for the Movers are conceptually related to positive outcomes for deinstitutionalisation. The Academic and Maths increases may seem at first tangential to successful deinstitutionalisation for people with mild intellectual disability of this age but there has been consistent evidence in the adaptive behaviour literature of significant increases in academic skills after deinstitutionalisation (Lynch, Kellow & Wilson, 1997; Kim, Larson & Lakin, 2001). These increases in ability have been reflected in increases in self-concept for the people with mild intellectual disability who have been deinstitutionalised.

The use of a multi-dimensional self-concept instrument to determine the impact of deinstitutionalisation upon the self-concepts of people with mild intellectual disabilities is important. The SDQ-III measured self-concept from a multi-dimensional view of self, which allowed comparisons within and between subjects with respect to different facets of development and competence. Newer developments in self-concept theory indicate that such specificity is needed when considering the impact of disability and deinstitutionalisation upon the development of self-concept. Tracey (2001) found that only the academic self-concept of children with mild intellectual disabilities was affected by placement in different educational settings.

Previous research has demonstrated that global self-concept is not a useful construct (Marsh & Johnston, 1993). Global self-concept cannot reflect the diversity of multi-dimensional self-concept. Multi-dimensional self-concept is more useful in terms of different settings, behaviours, and interventions (Marsh & Johnston, 1993). However, Marsh and Johnston (1993) did not advocate the abandonment of measures of global self-concept, just that there needed to be more emphasis on multi-dimensional self-concept.

The successful use of an instrument that measures multi-dimensional self-concept for people with disabilities implies that this instrument be utilised to allow comparisons with non-disabled and other populations. It may also overcome the conflicting results that have been found for people with intellectual disabilities because of the continued use of unidimensional instruments in that field. It must be recognised though, that the instrument must be administered one to one, if reliable and valid responses are to be recorded.

Locus of Control

These results do not support the literature that suggests that moving to independent living leads to greater choices and more autonomy for people with intellectual disabilities which is then reflected in a more internal locus of control (Wehmeyer & Bolding, 1999). The results do support the previous research that people with intellectual disabilities hold highly external perceptions of control and that these are maintained across the lifespan. The participants in this study could be

conceptualised as having maladaptive perceptions of control. These may be the result of the lack of opportunities that these people have experienced as a result of their long histories of institutionalisation. Another explanation may be that they do not fully understand that effort and ability can have a significant influence on positive outcomes and they more readily believe in external choices like luck, chance and fate (Wehmeyer & Palmer, 1997). It could be that their perceptions are realistic.

These results do not support the abandonment of the locus of control construct when conducting research with people with intellectual disabilities. Internal locus of control is still considered to be closely related conceptually to quality of life and self-determination (Wehmeyer & Schwartz, 1997). The lack of change in the locus of control construct could suggest that it is necessary to strengthen services in this area that could affect this construct. An alternative explanation could be that the measure used in this study, although the one that has been used exclusively for this population, was not appropriate.

Quality of Life

The findings from this study support previous research in relation to the impact of deinstitutionalisation on quality of life. The study confirmed the previous findings of studies conducted within Australia (Young et al., 1998), Britain (Emerson & Hatton, 1996) and the USA (Kim et al., 2001), in that living in the community leads to positive changes associated with quality of life. Specifically, this study found that, as hypothesised, the quality of life of the Movers increased in the domains of Objective Community and Objective Material, and Subjective Material and Subjective Safety. These results support the results of others that the domains of quality of life most likely to be affected by deinstitutionalisation were material well-being and community integration (Apgar, Cook & Lerman 1998). It is also encouraging that the Movers thought that their Safety was increased, as one of the reasons for keeping people in institutions was their perceived vulnerability in the community.

Adaptive Behaviour

There were statistically significant improvements in both adaptive behaviour and challenging behaviour for the Movers because of the change to community living. This increase in adaptive behaviour scores is common and is well-documented in the literature (Young et al., 1998; Kim et al., 2001).

Another important finding of this study was the statistically significant improvement in Social Challenging Behaviour and the lack of change (no increase) in Personal Challenging Behaviour. This finding has not been shown in Australian studies before, as the most recent Australian studies reported increases in challenging behaviours as well (Young et al., 2001). These results mirror the recent studies in USA which have shown that the challenging behaviour problem that was evident in the 1980s has not been found in the last 10 years because of improved support in the community. Most recent studies have shown no significant change or significant improvements (Kim et al., 2001). For this study the results on the adaptive behaviour factors and challenging behaviour factors indicate that the Movers had made a successful adjustment to community living. This positive outcome for challenging behaviour in studies overseas and this research are unlike that found previously in Australia (Young et al., 1998). Perhaps the shift towards person-centred services and person-centred planning that was instituted for the Movers had reduced the need for the expression of challenging behaviour. In summary, the results on the AAMD-ABS are an internally consistent validation of the impact of relocation on real-life social behaviours.

Conclusions

The results in this study present a coherent picture of the impact of deinstitutionalisation. The question must be asked regarding these affective variables irrespective of the policy of normalisation: how statistically significant should each of these be to justify the move into the community from an institutionalised setting? This study clearly demonstrated that although accepting the limitations of the results of some of the factors within even the multidimensional instruments, there were no advantages for people who stayed behind in the institutions.

The results support the measures used to identify the effects of deinstitutionalisation. The results (i.e. no change or very little change in the Stayers and either no change or changes in the hypothesised direction for the Movers) validate the measures. Psychological well-being of clients has been in the past neglected because of problems with instrumentation (Zetlin, Heriot & Turner, 1985, Zetlin & Turner, 1988). With the advent of theoretically sound and more robust instrumentation, this can no longer be justified.

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