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Presenting the Evidence

Deinstitutionalisation:

A Review of Literature

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Vision:

We have a vision of families being agents of positive social change so that people with developmental disability have inherent value as members of a just and inclusive society.

Mission:

To attain positive social roles for people who have a developmental disability through the development and support of advocacy by families and by strengthening the knowledge, role and influence of the family.

Executive Summary

Introduction

The 1998 NSW Government decision to close institutions was hailed as a socially just decision. It provided hope for a better future for the 2,600 residents and for the thousands of children, young people and adults with disability who may have been placed in these institutions for want of alternative options in the community.

The decision rested on the seminal work of the then NSW Community Services Commission that exposed the draconian state of NSW institutions which failed to protect the human and legal rights, safety and dignity of residents with intellectual disability. The *Performance Audit Report of Large Residential Centres for People with a Disability in NSW* recognised that even if minimum standards and adequate policies are developed,

> *there are other factors which are inherent to institutional models of care that are difficult to remedy. These include the whole of life umbrella approach to the delivery of services, the custodial and impersonal nature of care, their segregation from the community, their inability to provide a homelike environment and their increased difficulty in meeting the physical, emotional, social and skill development needs of residents.*
>
> *These features of institutional care mean that even if centres met the requirements of basic safety and rights, institutions could never meet the individual needs of people with a disability or provide the quality of life envisaged by the Disability Services Act 1993* (Audit Office & Community Services Commission:1998:ix).

Since that time, the implementation of minimum standards has diverted attention away from the need to close institutions and hence the government decision to redevelop rather than close three institutions, has largely passed unnoticed.

The purpose of this paper is to use the evidence of research to remind government of the original reason for closing institutions. That is, at minimum, to protect the human and legal rights, safety and dignity of people with disability and to meet the requirements of the *NSW Disability Services Act, 1993* (DSA). The DSA requires services to enable people with disability to achieve their maximum potential and positive outcomes such as increased independence, employment opportunities and integration into the community. In addition, it requires services to be provided in such a way as to provide a positive image of persons with disabilities and to enhance their self esteem.

Key messages from the literature of deinstitutionalisation

Major studies in the UK, Ireland and USA have examined the outcomes for people with disability who are relocated from large residential centres to live in the community. Such studies report a substantial reduction in the numbers of people living in large residential centres confirming clearly that the practice of deinstitutionalisation has been accepted and adopted widely in the USA and most if not all European countries (Hatton & Emerson:1996:17).

This report draws on evidence presented by Emerson and Hatton (1996) in their meta-analysis of the UK research literature on the effects of deinstitutionalisation, published between 1980 and 1994, on evidence presented by Kim, Larson and Lakin (2001) in their meta-analysis of US literature on behavioural outcomes of deinstitutionalisation between

1980 and 1999 and on the as yet unpublished analysis by Lemay of the literature in Canada.

In total, these reviews present the evidence of over 100 studies reported in peer reviewed journals that indicated that:

> *Smaller, community based residential services were generally, though not inevitably associated with increased user engagement in ongoing activities, increased contact with care staff, increased use of community facilities, increases in adaptive behaviour, reductions in observed challenging behaviour, increased opportunities for choice, increased contact with family and friends, a better material standard of living and an increased acceptance by the community.* (Emerson & Hatton:1996:17)

Studies that examined family attitude to deinstitutionalisation have found that:

- parents who were initially opposed to deinstitutionalisation were almost always satisfied with the results of the move to the community after it occurred (Larson & Lakin:1989; Larson & Lakin:1991);
- family preference for community based services increased significantly over time (Tossebro:2006);
- family contact increased significantly when people moved out of institutions into the community and remained higher even after several years of placement in the community (Stancliffe & Lakin:2006);
- when many people had moved out of the institution, family contact decreased for people who stayed in the institution (Stancliffe & Lakin:2006).

Stancliffe and Lakin suggest that carefully supporting family (re)involvement during the relocation process may be associated with stable long term family contact (Stancliffe & Lakin:2006).

It is time to apply evidence based practice to services for people in large residential centres. The unequivocal message from research is that people who have moved out of institutions have a better quality of life and better outcomes than people living in institutions.

The evidence provides two important lessons for government. Firstly, that people with disability have better lives, measured in a myriad of ways, when they move out of institutions. Secondly, that whilst most families oppose the move to close institutions (change is always hard), families change their mind about its benefits after the move and become more and more committed to community living as time goes by.

In this context, the redevelopment of institutions into a village for seventy people with challenging behaviour, a retirement village for a hundred people with intellectual disability and a twenty bed unit for people with complex health needs cannot be justified. These Australian citizens deserve better. Even if part of the pressure for redevelopment comes from families of current residents, "considerations of intergenerational equity require their closure so that redevelopments of today do not put a noose around the neck of the future generations who will be placed in institutional care in spite of wanting a community based option." (Bostock:2001:53).

Introduction

Major studies in the UK, Ireland and USA have examined the outcomes for people with disability who are relocated from large residential centres to live in the community. The studies report a substantial reduction in the numbers of people living in large residential centres confirming clearly that the practice of deinstitutionalisation has been accepted and adopted widely in the USA and most if not all European countries (Hatton, Emerson & Kiernan, 1995 in Emerson:1996:17).

Despite the depopulation and closure of institutions, deinstitutionalisation continues to be a controversial topic in states that operate such services (Kim, Larson & Lakin:2001:36). The reasons for the controversy are multiple. The best interests of people with disability must battle conflicting interests of more powerful groups. Families of current residents are nervous: forced to relive the tension at the time of placement, they distrust government commitments to provide long term support; staff of institutions are nervous that they will find it hard to reorient themselves to the new demands of community living or will lose their jobs when institutions close; towns in which institutions are situated are nervous at the impact of closure on the economic and social fabric of the community and people with little prospect of government funded accommodation support wonder why all this fuss is made on behalf of people 'who at least have something'.

Among this controversy and conflict, the neglectful and abusive situation of life in institutions is forgotten. In NSW, it was the seminal work of the then NSW Community Services Commission exposing the draconian state of NSW institutions for people with disability that led the Minister for Disability Services in 1998 to commit to close institutions over twelve years.

The work to close the institutions progressed slowly, although thirteen institutions have closed since that time (DADHC:2007:2). In 2007, 1720 people with intellectual disability continue to live in thirty three institutions. Any government enthusiasm for closure has dimmed and significant new resources have been committed to the redevelopment of three large residential centres that in 1998 had been priorities for closure.

It is not surprising that the interests of people with disability were unable to withstand the onslaught of conflicting powerful interests. The faltering processes of government led to doubt that government had the knowledge and skills to successfully accomplish the closures and the significant unmet need for accommodation support made many question the monumental size of the task.

The case for closure is based on three elements:

- Human rights considerations require that people with disability are afforded the same opportunities as other citizens;
- There is a requirement for evidence based practice. DADHC claims adherence to this principle in the NSW Government *Accommodation and Support Paper* (2006) with its commitment that "Research and evidence will inform service development and practice" and "Accommodation and support options will build on practice that works for people with disability – both nationally and internationally."
- There is a need to ensure "inter-generational equity and sustainability in housing options so that redevelopments of today do not lead to a noose around the neck

> of the future generations who will be placed in institutional care in spite of wanting a community based option." (Bostock:2001:53

The report draws on evidence presented by Emerson and Hatton (1996) in their meta-analysis of the UK research literature on the effects of deinstitutionalisation, published between 1980 and 1994, on evidence presented by Kim, Larson and Lakin (2001) in their meta-analysis of US literature on behavioural outcomes of deinstitutionalisation between 1980 and 1999 and on the as yet unpublished analysis by Lemay of the literature in Canada. In total, these reviews present the evidence of over 100 studies reported in peer reviewed journals that indicated that "smaller, community based residential services were generally, though not inevitably associated with:

- increased user engagement in ongoing activities;
- increased contact with care staff;
- increased use of community facilities;
- increases in adaptive behaviour;
- reductions in observed challenging behaviour;
- increased opportunities for choice;
- increased contact with family and friends;
- a better material standard of living; and
- increased acceptance by the community." (Emerson & Hatton:1996:17)

Finally, the paper reviews research that demonstrates that parents who were initially opposed to deinstitutionalisation were almost always satisfied with the results of the move to the community after it occurred (Larson & Lakin:1989; Larson & Lakin:1991)

The conclusion of the research, which must underpin evidence based practice is unequivocal. The best interests of people with disability are served by the closure of all large residential centres.

The studies included in this review show a diverse range of approaches to measuring the impact of deinstitutionalisation on the quality of life of service users. To provide a basis on which to make comparisons, measures of outcomes were categorised according to the following general domains.

Engagement

Studies typically define engagement as either appropriate non social activity (such as participation in leisure activity, personal care, domestic activity or an appropriate response to a formal program) or social interaction between the user and others. Engagement has been the most frequently used measure of outcome in UK research since the 1980s and is measured as the extent to which users are actively engaged or participating in every day ongoing activities. It is measured by the direct observation of a person not involved in the group (direct non participant observation). (Emerson & Hatton:1996)

Even though a substantial variation occurred within each type of service, results indicate that overall, the type of service had a significant effect on the level of engagement. People in staffed houses had a higher level of engagement than people in units/hostels who in turn had a higher level of engagement than people in NH hospitals/institutions. (Studies by Emerson, Cooper & Hatton:1995; Felce et al.:1980; Felce, de Kock, & Repp: 1986; Mansell:1994; Felce, Kushlick & Mansell:1980, Emerson et al.:1995 (reported in Emerson & Hatton:1996), Hatton, Emerson Robertson, Henderson & Cooper(1996)

Staff contact

Twenty six studies examined the extent and nature of contact received by users from care staff, most frequently employing non-participant direct observation (Emerson, Beasley, Offord & Mansell:1992; Felce, Mansell & Kushlick:1980; Felce et al.:1986, Mansell:1994 reported in Emerson & Hatton:1996).

Overall levels of staff contact were higher in staffed houses than either units/hostels or NH hospitals/institutions. Again however, substantial variation was apparent within models. Whilst the small number of studies evaluating staff contact in hostels and units makes the assessment of the statistical significance of differences across all types of services impossible, a comparison of institutions with staffed houses revealed that users in staffed houses received significantly more staff contact than users in NHS hospitals.

Opportunities for choice

Twelve studies contained some consideration of the opportunities for choice available to service users across different types of services. Methods used to evaluate opportunities for choice varied widely and included qualitative interviews with service users (Flynn: 1989), families (Emerson et al:1995) and staff (Dockerall, Gaskell, Rehman & Normand, :1993), quantitative rating scales (Beswick:1992), physical indicators assumed to correspond to service user choice (Felce, Thomas, de Kock, Saxby & Repp:1985) and the amount of time services users' living arrangements were locked (Murphy, Holland, Fowler & Reep:1991) (reported in Emerson & Hatton:1996).

Studies using a loose definition of autonomy and those which have focused on choice over routine daily activities have typically reported greater autonomy and choice in less institutional settings, although this may be more restricted than the general population (Emerson & Hatton:1996:28).

Studies concerning choice over important life decisions report users as having little choice over these broad aspects of their lives (Cattermole, Johoda & Markova, 1998)

Relationships

Ten studies investigated some aspect of relationships between service users and others. The studies recorded contact between service users and family/friends though diary records of carers (de Kock et al.:1988; Lowe & de Paiva1991; Cattermole et al:1988; Fleming & Stenfert Kroese:1990) and through interviews conducted with service users or with relatives (Cattermole et al., 1988; Flynnn:1989 reported in Emerson & Hatton:1996).

Those studies that have examined the frequency of contact between service users, friends and relatives have generally reported an increased frequency of social contacts in less institutional settings (de Kock et al.:1988; Lowe & de Paiva:1991). They have also reported however, that frequency of such contact, particularly with people who are not other residents, staff or relatives, remains very low in community settings (Lowe & de Paiva:1991; Cattermole et al.:1988; Fleming & Stenfert Kroese:1990).

Those studies that have examined the depth of social relationships have reported that relationships with people without developmental disability outside the family are either superficial or generally not existent (Cattermole et al.:1988; Jahoda et al:1990).

Satisfaction

Seven studies evaluated either users' satisfaction with the services they were receiving or their satisfaction with life in general, primarily through qualitative interviewing techniques (Flynn:1989; Jahold et al:1990). Overall, studies have reported improvement in user satisfaction with services associated with moves from hospital to community based services. Studies also reported similar improvements in satisfaction with lifestyle and life in general (Beswick:1992; Cullen et al. in Emerson & Hatton:1996).

Social indicators

Social indicators are those measurable 'objective' indices which, by consensus are thought to be associated with a better quality of life. Seven studies examined some aspect of physical environment of settings. Not surprisingly, such studies reported that community based services are more 'normalised' than hospital settings, and that the quality of the physical environment in community based settings is higher than the quality of the physical environment in the hospital settings (Beswick:1992; Conneally et al:1992; Flynn:1989; Sinson:1990 reported in Emerson & Hatton:1996).

Adaptive behaviour

Twenty six UK studies examined some aspect of the personal competence of service users primarily through the use of questionnaires and rating scales.

Whilst the majority of studies (67%) reported increased personal competence following the move to less institutional settings, a significant minority (33%) reported no such difference. The few studies that have evaluated changes in personal competence of service users over an extended period of time (Cambridge, Hayes & Knapp, 1993; Hemming, 1986, Lowe, de Paiva & Felce, 1993 reported in Emerson & Hatton:1996) have tended to report a 'plateau' effect, in which large initial gains resulting from the move to community based services are followed by few additional changes once service users are living in the community based services. Such results suggest that increases in adaptive behaviours may reflect the increased opportunities available to service users in community settings, rather than the continued development of the competence, skills and abilities of service users over time.

US studies note that overall adaptive behaviour was almost always found to improve with movement to community settings from institutions (Larson & Lakin:1989; Larson & Lakin:1991). The meta-analysis of 11 studies of specific adaptive behaviour skills found that self care skills, and to a lesser degree, communication, academic skills, social skills, community living and physical development improved significantly with deinstitutionalisation (Lynch, Kellow & Wilson, 1997 in Kim, Larson & Lakin:2001:36).

Twelve US studies compared people who moved from institutions to small residential settings with a 'contrast' group of people who stayed in the institution (Kim, Larson & Lakin:2001:39).

The findings regarding outcomes within specific domains of adaptive behaviour among the contrast group studies showed movers with either statistically significant improvements relative to stayers or with improvements that did not reach statistical significance. As the Lynch et al (1997) meta-analysis reported, self care or domestic skills domain of adaptive behaviour showed most consistent statistically significant improvements. Other adaptive behaviour domains that showed statistically significant improvements in at least two separate studies included academic skills, community living skills, social skills and vocational skills (Kim, Larson & Lakin:2001:39).

Other US studies measured changes in adaptive behaviour over time (longitudinal studies). Twenty two longitudinal studies examined changes in adaptive behave among people who had moved from institutions. Thirteen reported statistically significant improvements in overall adaptive behaviour associated with moving to a small community setting and two reported significant declines (Kim, Larson & Lakin:2001:39).

Fourteen US studies examined changes in adaptive behavior in specific domains. Whilst contrast group studies found the most consistent pattern of improvements in self care or domestic skills, among longitudinal studies, social skills showed most consistent improvement. Six of the seven longitudinal studies that measured social skills found statistically significant improvements after movement to community and the seventh found improvements that did not reach statistical significance. Five studies looked at community skills and reported statistically significant improvements while an additional four studies reported statistically significant improvements in vocational skills associated with deinstitutionalisation (Kim, Larson & Lakin:2001:39).

Challenging behaviour

In the UK studies, two complimentary approaches have been taken to evaluate the impact of deinstitutionalisation on the extent and nature of challenging behaviour shown by service users. The majority of studies used standardized rating scales to solicit information from key informants, such as care staff (Murphy & Clare:1991). A smaller number of studies directly observed the service users over varying periods of time to measure changes in the amount of time users exhibited challenging behaviour (Emerson et al:1992; Mansell:1994 reported in Emerson & Hatton:1996).

The two different approaches give very different results. The use of information from third parties suggests that the move from more to less institutional settings is associated with no change in the challenging behaviours shown by users. For a minority of comparisons between hospitals and staffed housing, this approach resulted in the reporting of a significant increase in challenging behaviours following the move to smaller community based services.

In contrast, those studies which directly observed service users reported an overall reduction in challenging behaviour associated with the move to community based services although this was only the case for three of the seven comparisons.

Emerson & Hatton (1996) identify a number of factors that may account for these discrepancies. These include: differences in skills, expectations and experience between informants in the institutional and community-based settings, increased opportunity for certain forms of challenging behaviour in less institutional settings, increased social disruption caused by certain forms of challenging behaviour in less institutional settings, increased rates of some eliciting events (eg social demands) in community based settings and differential sensitivity of measurement approaches to different forms of challenging behaviour.

The twelve US contrast studies (compared people who moved from institutions to small residential settings with a 'contrast' group of people who stayed in the institution (Kim, Larson & Lakin:2001:39) found that only one study reported a difference in challenging behaviour between stayers and leavers that was statistically significant. In that study, movers stayed the same while the stayers had overall challenging behaviour ratings that declined significantly.

Longitudinal measures of general challenging behaviour found the same variability as reported for contrast group studies. Ten studies showed improvements in challenging behaviour after the move, including three studies in which changes were statistically significant after 6, 9, 36 and 72 months. On the other hand, six studies reported increased levels of challenging behaviour after the move, including two studies (in 1980s) that reported significant increases.

The more recent US studies have noted somewhat different outcomes in relation to challenging behaviour than the results of studies in the 1980s. Since 1990, twelve studies tested changes in overall challenging behaviour associated with movement to community. Three studies found statistically significant improvements whilst the rest found no change. Kim et al (Kim, Larson & Lakin:2001) argue that these findings are important because a common argument against deinstitutionalisation is that challenging behaviour will deteriorate when the person moves. Studies of deinstitutionalisation in the US in the 1990s indicate that challenging behaviour either improves or has no change (Kim, Larson & Lakin:2001).

Other outcomes

Other outcomes reported from studies of people who have moved from institutions into the community include improved material well-being and community integration (Apgar, Cook & Lerman:1998); improved social presence and significantly higher overall quality of life, satisfaction, productivity, independence and integration (Conroy, Lemanowicz, Feinstein & Bernotsky (1991); more opportunities to make to make choices (Conroy:1995) and increased use of community spaces, engagement in more social activities, more personal integration and more family contacts (Stancliffe & Lakin:1998) reported in Kim, Larson & Lakin:1991:46).

Family attitudes

US research demonstrates that families of people with developmental disabilities oppose deinstitutionalisation, but that they change their minds after resettlement has taken place. In a review of twenty seven studies of parental attitudes on the deinstitutionalisation of a family member with disability, Larson & Lakin (1991) found high levels of satisfaction with institutional placement and opposition to deinstitutionalisation, whereas studies of community placements found high levels of satisfaction with community placements and retrospectively reported lower satisfaction with institutional placements.

This US pattern of initial opposition and 'after the fact' support is largely replicated in Scandanavian research by Tossebro (2006) whose longitudinal study found that the preference for community services was long term. Collecting family data before re-settlement and at five and ten years, Tossebro found that prior to resettlement only 17% of families preferred community care, five years later, 73% of families preferred community care and ten years later, 76% of families preferred community care. These results are supported in other studies (Grimes & Vitello, 1990, O'Brien, Thesing, Tuck & Capie, 2001; Spreat & Conroy, 2002; Conroy, Spreat, Yuskauskas & Elks, 2003 in Lemay:2006) which report that within as little as six months and up to seven years later, families who had opposed deinstitutionalisation had, at the very least, become reconciled to it and in some cases very supportive of community living.

Australian research conducted by Tabatabainia (Lemay:2006) identified four reasons why families opposed de-institutionalisation; namely:

- fear of a deleterious impact on their family life believing they would once again be responsible for the deinstitutionalized resident;
- concern for the welfare of the deinstitutionalized resident fearing change might lead to trauma and that relocation might be worse;
- fear that community services were inadequate and not up to the job of caring for their handicapped family member and relatedly that there was insufficient funding to ensure adequate services;
- satisfaction that institutional services were "very good".

Tabatabainia suggested that, at least in this case, the government had not done a good job of informing parents about the deinstitutionalisation process and the services to be found in the community, and had not done a good job of educating parents about normalisation and the proposed outcomes of deinstitutionalisation" (Lemay:2006:3).

Studies by Spreat & Conroy (2002) and Stancliffe & Lakin (2006) report that family contact increased when people moved out of institutions into the community and remained higher even after several years of placement in the community. Wolfensberger (2003) argues that family presence and participation in a handicapped person's life can be the single most important safeguard for the security and service quality and serves as a protective factor.

Stancliffe & Lakin (2006) examined the frequency and stability of family contact with long term institutional residents during a major deinstitutionalisation project. Whilst there was no difference in family contact prior to the move, data provided at four annual assessments demonstrated that family contact increased significantly for people who moved and decreased for people who stayed.

Stancliffe and Lakin suggest that carefully supporting family (re)involvement during the relocation process may be associated with stable long term family contact.

Discussion and Conclusion

The twenty first century is the time for evidence based practice in human services. Every proposal, every tender begins with the documentation of evidence to support the intended direction.

It is time to apply evidence based practice to services for people in large residential centres. Even though there has been some variation in the experiences of people within different service types, the unequivocal evidence from research is that people who have moved out of institutions have a better quality of life and better outcomes than people living in institutions.

The variation within models is testimony to the fact that size of living arrangement makes a difference but does not of itself guarantee good outcomes. Other research (Mansell:2005; Felce:1998) demonstrates the critical nature of inter-related aspects of staffing. These include the size of the staff:resident group, the staff:resident ratio, how staff are deployed (planning how to allocate staff to support resident activity) and how staff are trained and assisted to provide effective support to help people who lack skills to accomplish an activity.

In addition, there is some evidence that large initial gains resulting from the move to community based services are followed by few additional changes once service users are living in community based services. This plateau effect suggests that increases in adaptive behaviours may reflect the increased opportunities available to service users in community settings rather than continued development of competence, skills and abilities of service users over time. Even if improved adaptive behaviour is due in part to changes in environmental opportunities, one of the reasons that deinstitutionalisation is such a important policy is that it seeks to maximise inclusion for people with disability.

Deinstitutionalisation has largely been accepted in the US, UK, most of Europe and most of Australia and this paper has provided the evidence of its efficacy and effectiveness. This provides two important lessons for government. Firstly, that people with disability have better lives, measured in a myriad of ways, when they move out of institutions. And secondly, that whilst most families oppose the move to close institutions (change is always hard), families change their mind about its benefit after the move. Evidence confirms that families become more and more committed to living in the community as time goes by.

Bibliography

Emerson, E. & Hatton, C.,(1996) Deinstitutionalisation in the UK and Ireland: Outcomes for Service users, *Journal of Intellectual and Developmental Disability,* 21 (1) 17-37

Kim, S., Larson, S.A. & Lakin, K.C., (2001) Behavioural outcomes of deinstitutionalisation for people with intellectual disability: A review of US studies conducted between 1980 and 1999, *Journal of Intellectual and Developmental Disability, 26(1) 35-50*

Lemay, R (2006) *Deinstitutionalisation: A Brief review of the current literature and commentary*, unpublished NSW Government *Accommodation and Support Paper* (2006) http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Models+of+Supported+Accommodation+for+People+with+a+Disability.htm

Articles cited

Apgar, D.H., Cook, S., & Lerman, P. (1998). *Life after Johnstone: impacts on consumer competencies, behaviours and quality of life.* Neward, NJ: New Jersey Institute of Technology, Centre for Architecture and Building Science Research.

Beswick,J. (1992). Unpublished doctoral dissertation. University of Manchester, Manchester, England.

Bolin, B.L. (1994). Developmental disabilities quality assurance: a study of deinstitutionalisation. Unpublished Doctoral Dissertation. Stillwater, OK: Oklahoma State University.

Booth, W., Boot, T., & Simons, K. (1990). Return journey: the relocation of adults from long-stay hospital into hostel accommodation. *British Journal of Mental Subnormality, 36,* 87-97.

Bradley, V.J., Conroy, J.W., Covert, S.B., & Feinstein, C.S. (1986). *Community options: the New Hampshire choice.* Cambridge, MA: Hman Services Research Institute.

Bratt, A., & Johnston, R. (1988). Changes in life style for young adults with profound handicaps following discharge from hospital care into a 'second generation' housing project. *Mental Handicap Research, 1,* 49-74.

Burchard, S. N. (1999). Normalization and residential services: The Vermont studies. In R. J. Flynn & R. A. Lemay (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact.* Ottawa, ON: University of Ottawa Press.

Business Services Group (1999). *Longitudinal quality of life study: Phase III.* Sacramento, CA: Business Services Group, California State University, Sacramento.

Calapai, P. (1988). Adaptive behaviors of developmentally disabled adults living in community residences. Unpublished Doctoral Dissertation. Hofstra University Hempstead NY.

Cambridge, P., Hayes, L., & Knapp, M. (1993). *Care in the community: five years on.* Canterbury, England: Personal Social Services Research Unit, University of Kent at Canterbury.

Cattermole, M., Jahoda, A., & Markova, I. (1988). Leaving home: the experiencee of people with a mental handicap. *Journal of Mental Deficiency research, 32,* 47-57.

Centre for Outcome Analysis (1999). *The Indiana quality tracking project on DC closures: preliminary findings.* Bryan Mawr, PA: Centre for Outcome Analysis.

Close, D.W. (1977) Community living for severely and profoundly retarded adults: a group home study. *Education and Training of the Mentally Retarded, 12,* 256-262.

Coland, J.S., & Weisler, N.A. (1995). Preventing restrictive placements through community support services. *American Journal of Mental Retardation, 100,* 201-206.

Colorado Division of Developmental Disabilities (1982). *Colorado's regional centre satellite group homes: an evaluation report.* Denver: Author.

Conneally, S., Boyle, G., & Smyth, F. (1992). An evaluation of the use of small group homes for adults with a severe and profound mental handicap. *Mental Handicap Research, 5,* 146-168.

Conroy, J., Spreat, S., Yuskauskas, A., and Elks, M. (2003). The Hissom Closure Outcomes Study: A Report on Six Years of Movement to Supported Living. *Mental Retardation: 41*(4), 263–275.

Conroy, J.W. (1995). *The Hissom outcome study: a report on six years of movement into supported living. The well-being of people with developmental disabilities in Oklahoma* (Brief Report no. 1). Ardmore, PA: Centre for Outcome Analysis.

Conroy, J.W. (1998) *Are people better off? Outcomes of the closure of Winfield State Hospital.* Report submitted to the Kansas Council on Developmental Disabilities. Rosemont, PA: Centre for Outcome Analysis.

Conroy, J.W., & Bradley V.J. (1985) *The Pennhurst longitudinal study: a report of five years of research and analysis.* Philadelphia: Temple University Developmental Disabilities Centre. Boston: Human Services Research Institute.

Conroy, J., Efthimiou, J, & Lemanowicz, J. (1982). A matched comparison of the developmental growth of institutionalized and deinstitutionalized retarded clients. *American Journal on Mental Deficiency, 86,* 581-587.

Conroy, J.W., Feinstein, C.S., & Lemanowicz, J.A. (1988). *Results of the longitudinal study of CARC v Thorne class members* (Report no. 7), Philadelphia: Temple University, Developmental Disabilities Centre.

Conroy J.W., Lemanowicz, J.A., Feinstein, C.S., & Bernotsky, J.M. (1991). *1990 results of the CARC v Thorne longitudinal study. The Connecticut Applied Research Project* (Report no. 10) Narberth, PA: Conroy & Feinstein Associates.

Conroy, J.W., Seiders, J., & Yuskauskas, A. (1998). *Patterns of community placement IV: the fourth annual report on the outcomes of implementing the Coffelt settlement agreement* (Report no. 17). Bryn Mawr, PA: Centre for Outcome Analysis.

Cullen, C., Whoriskey, M., Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S., & Stanley, A. (1995). The effects of deinstitutionalisation on adults with learning disbilities. *Journal of Intellectual Disability Research, 39(6),* 484-494.

Cullen, C., Whoriskey, M., Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S., & Stanley, A. (in press). The effects of deinstitutionalisation for adults with mental retardation. *Jurnal of Intellectual Disability Rersearch, 39,* 484-494.

Cummins, R.A., Polzin, U., & Theobald, T. (1990). The deinstitutionalisation of St.Nicholas hospital III: four year follow-up of life-skill development. *Australia and New Zealand Journal of Developmental Disabilities, 16(4),* 219-232.

D'Amico, M.L., Hannah, M.A., Milhouse, J.A. & Froleich, A.K. (1978). *Evaluation of adaptive behaviour. Institutional vs. community placements and treatment for the mentally retarded.* Stillwater, OK: Oklahoma State University, National Clearing House of Rehabilitation Materials.

Cullen, C., Whoriskey, M., Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S., & Stanley, A. (in press). The effects of deinstitutionalisation for adults with mental retardation. *Jurnal of Intellectual Disability Rersearch, 39,* 484-494.

Davies, L. (1988). Community care: the costs and quality. *Health Services Management Research, 1,* 145-155.

De Kock, U., Saxby, H., Thomas, M., & Felce, D. (1988). Community and family contact: An evaluation of small community homes for adults with severe and profound mental handicaps. *Mental Handicap Research, 1,* 127-140.

Department of Health (1993). *Services for people with learning disabilities and challenging behaviour or mental health needs.* London: HMSO.

Dockrell, J., Gaskell, G., Rehman, H., & Normand, C. (1993). Service provision for people with mild learning difficulty and challenging behaviour: the MIETS evaluation. In C. Kiernan (Ed.) *Research to practice?* Clevedon: BILD.

Drukin, M. S. (1996). Editorial: Beyond mortality-residential placement and quality of life among children with mental retardation. *American Journal of Public Health, 86*(10), 1359-1360.

Eastwood, E.A., & Fisher, G.A. (1988). Skill acquisition among matched samples of institutionalized and community-based persons with mental retardation. *American Journal on Mental Retardation, 93,* 75-83.

Emerson, E. (2004) Deinstitutionalisation in England. *Journal of Intellectual & Developmental Disability, 29*(1) 79-84.

Emerson, E., Kiernan, C., Alborz, A. Reeves, D., Mason, H., Swarbrick, R., Mason, L., & Hatton, C. (2001). The prevalence of challenging behaviors: a total population study. *Research in Developmental Disabilities, 22*(1), 77-93.

Emerson, E., & Hatton, C. (1996). Deinstitutionalisation in the UK and Ireland: outcomes for service users. *Journal of Intellectual and Developmental Disability 21(1),* 7-37.

Emerson, E. (1985). Evaluating the impact of deinstitutionalisation on the lives of mentally retarded people. *American Journal of Mental Deficiency, 90,* 277-288.

Emerson, E., & Hatton, C. (1994). *Moving out: the impact of the move from hospital to community on the quality of life of people with learning difficulties.* London: HMSO.

Emerson, E., Beasley, Fl, Offord, G., & Mansell, J. (1992). Specialised housing for people with seriously challenging behaviours. *Journal of Mental Deficiency Research, 36,* 291-307.

Emerson, E., Cooper, J., & Hatton, C. (1995). Quality and costs in a residential further education facility for people with dual sensory impairments. *Journal of Visual Impairment and Blindness, 89,* 402-416.

Feinstein, C.S., Lemanowicz, J.A., DeRosa, C.S., & Clarke, A.F. (2000). *Evaluation of the well-being of people who moved from Pennsylvania's state facilities to the community in 1998.* Philadelphia: Temple University, Institute on Disabilities (UAP).

Feinstein, C.S., Lemanowicz, J.A., Spreat, S., & Conroy, J.W., (1986). *Report to the special master in the case of Gary W. v. the State of Louisiana.* Philadelphia: Temple University, Developmental Disabilities Centre.

Felce, D., Lowe, K., Beecham, J., & Hallam, A. (2001) Exploring the relationships between costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviors in Wales: A multivariate regression analysis. *Journal of Intellectual & Development Disability, 26*(1) 109.

Felce, D., & Perry, J. (1996). Adaptive behaviour gains in ordinary housing for people with learning disabilities. *Journal of AApplied Research in Intellectual Disabilities, 9,* 101-114.

Felce, D. (1988). Behavioural and social climate in community group residences. In M.Janicki, M.W. Krauss & M.M. Seltzer (Eds.), *Community residences for persons with developmental disabilities.* Baltimore, MD: Paul H. Brookes.

Felce, D. (1989). *The Andover project: staffed housing for adults with severe or profound mental handicaps.* Kidderminster, England: British Institute on Mental Handicap.

Felce, D. (1991). Using behavioural principles in the development of effective housing services for adults with severe or profound handicap. In B. Remington (Ed.) *The challenge of severe mental handicap: a behaviour analytic approach.* Chichester, England: Wiley.

Felce, D. (in press). The quality of support for ordinary living: staff:resident interactions and resident activity. In J. Mansell & K. Ericson (Eds), *The dissolution of institutions: an international perspective.* London: Chapman and Hall.

Felce, D., & Perry, J. (1995). Quality of life: a contribution to its definition and measurement. *Research in Developmental Disabilities, 16,* 51-74.

Felce, D., Kushlick, A., & Mansell, J. (1980). Evaluation of alternative residential facilities for the severely mentally handicapped in Wessex: client engagement. *Advances in Behaviour Research and Therapy, 3,* 13-18.

Felce, D., Mansell, J., & Kushlick, A. (1980). Evaluation of alternative residential facilities for the severely mentally handicapped in Wessex: staff performance. *Advances in behaviour research and therapy, 3,* 25-30.

Felce, D., Thomas, M., de Kock, U., Saxby, H., & Repp, A. (1985). An ecological comparison of small community based houses and traditional institutions: physical setting and the use of opportunities. *Behaviour research and therapy, 23* 337-348.

Felce, D., de Kock, U., & Repp, A. (1986). An eco-behavioural analysis of small community based houses and traditional large hospitals for severely and profoundly mentally handicapped adults. *Applied Research and Therapy, 23,* 337-348.

Fleming, I., & Stenfert Kroese, B. (1990). Evaluation of a community care project for people with learning disabilities. *Journal of Mental Deficiency Research, 34,* 451-464.

Ferleger, D. & Boyd, P. A. (1980). Anti-institutionalzation: The promise of the Pennhurst case. In R. J. Flynn & K. E. Nitsch (Eds.), *Normalization, social integration, and community services* (pp. 141-166). Baltimore: University Park Press.

Flynn, R. J. (1980). Normalization, PASS, and service quality assessment: How normalizing are current human services? In R. J. Flynn & K. E. Nitsch (Eds.), *Normalization, social integration, and community services* (pp. 323-357). Baltimore: University Park Press.

Flynn, R. J., Lapointe, N., Wolfensberger, W., & Thomas, S. (1991). Quality of institutional and community human service programs in Canada and the United States. *Journal of Psychiatry and Neuroscience, 16*(3), 146-153.

Flynn, R. J. (1999). A comprehensive review of research conducted with the program evaluation instruments PASS and PASSING. In R. J. Flynn & R. A. Lemay (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact.* Ottawa, ON: University of Ottawa Press.

Flynn, R. J., & Aubry, T. D. (1999). Integration of persons with developmental or psychiatric disabilities: Conceptualization and measurement. In R. J. Flynn & R. A. Lemay (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact.* Ottawa, ON: University of Ottawa Press.

Flynn, M. (1989). *Independent living for adults with mental handicap: 'A Place of My Own'.* London: Cassell Educational.

Fortune, J., Heinlein, K.B., & Fortune, B. (1995). Changing the shape of the service population. *European Journal of Mental Disability, 2(8),* 20-37.

Fullerton, A., Douglass, M., & Dodder, R. A. (1999) A reliability study of measures assessing the impact of deinstitutionalisation. *Research in Developmental Disabilities, 20*(6) 387-400.

Grimes, S. K., & Vitello, S. J. (1990) Follow-up study of family attitudes toward deinstitutionalisation: Three to seven years later. *American Association on Mental Retardation, 28*(4) 219-225.

Haney, J.I. (1988). Empirical support for deinstitutionalisation. In L.W. Heal, J.I. Haney & A.R. Novak Amado (Eds.), *Integration of developmentally disabled individuals into the community.* Baltimore: Paul H. Brookes.

Hatton, C., Emerson, E., & Kiernan, C. (1995). Trade and milestones: deinstitutionalisation in Europe. *Mental Retardation, 33,* 132.

Hatton, C., Emerson E., Robertson, J., Henderson, D., & Cooper, J. (1995). *An evaluation of the quality and costs of services for adults with severe learning disabilities and sensory impairments.* Manchester: Hester Adrian Research Centre, University of Manchester.

Hatton, C., Emerson, E., Robertson, J., Henderson, D. & Cooper, J. (in press). The quality and costs of residential services for adults with multiple disabilities: a comparative evaluation. *Research in Developmental Disabilities.*

Hayden, M.F., DePaepe, P., Soulen, T., & Polister, B. (1995). *Deinstitutionaliztion and community integration of adults with mental retardation: summary and comparison of the baseline and one-year follow-up residental data for the Minnesota Longitudinal Study* (Project Report no. 1). Minneapolis: University of Minnesota, Research and Training Centre on Community Living.

Hemming, H. (1986). Follow-up of adults with mental retardation transferred from large institutions to new small units. *Mental Retardatiion, 24,* 229-235.

Horner, R.H., Stoner, S.K., & Ferguson, D.L. (1988). *An activity-based analysis of deinstitutionalisation: the effects of community re-entry on the lives of residents leaving Oregon's Fairview Training Centre.* Salem, OR: University of Oregon, Specialised Training Program of the Centre on Human Development.

House, J. S., Landis, K. R., & Umberson, D. (1990). Social relationships and health. In P. Conrad & R. Kern (Eds.) *The Sociology of Health & Illness: Critical Perspectives* (3rd Edition) (pp. 85-94). New York: St. Martin's Press.

Hughes, C., Bogseon, H., Kim, J-H., Eisenman, L., & Killian, D.J. (1995). Quality of life in applied research: a review and analysis of empirical measures. *Americal Journal on Mental Retardation, 99,* 623-641.

Jacobsen, J.W., @ Schwartz, A.A. (1991). Evaluating living situations of people with developmental disabilities. In J.L. Matson & J.A. Mulick (Eds.), *Handbook of mental retardation* New York: Pergamon.

Jahoda, A., Cattermole, M., & Markova, I. (1990). Moving out: an opportunity for friendship and broadenig social horizons? *Journal of Mental Deficiency Research, 34,* 127-139.

Janicki, M., Krauss, M.W., & Seltzer, M.M. (1988). *Community residences for persons with developmental disabilities.* Baltimore: Paul H. Brookes.

Kim, S., Larson, S. A., & Lakin, K. C. (2001) Behavioral outcomes of deinstitutionalisation for people with intellectual disability: A review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disability, 26*(1), 35-50.

Kinsella, P. (1993). *Supported living: a new paradigm.* Manchester, England: National Development Team.

Kleinberg, J., & Galligan, B. (1983). Effects of deinstitutionalisation on adaptive behaviour of mentally retarded adults. *Americal Journal of Mental Deficiency, 88,* 21-27.

Korman, N., & Glennerster, . (1990). *Hospital closure.* Milton Keynes, England: Open University Press.

Larson, S.A., & Lakin, K.C. (1989). Deinstitutionalisation of persons with mental retardation: behavioural outcomes. *Journal of the Association for Persons with Severe Handicaps, 14,* 324-332.

Larson, S.A., & Lakin, K.C. (1991), Parental attitudes about residental placement before and after deinstitutionalisation: a research synthesis. *Journal of the Association for Persons with Severe Handicaps, 16(1),* 25-38.

Lemay, R. A. (1995). Normalization and Social Role Valorization. In A. E. Dell Orto & R. P. Marinelli (Eds.), *Encyclopedia of Disability and Rehabilitation* (pp. 515-521). New York: Simon & Schuster Macmillan.

Lemay, R. A. (2006). Social Role Valorization (S.R.V.) Insights Into the Social Integration Conundrum. *Mental Retardation, 44(1), 1-12.*

Lerman, P., Apgar, D. H., & Jordan, T. (2005) Longitudinal changes in adaptive behaviors of movers and stayers: Findings from a controlled research design. *Mental Retardation, 43*(1) 25-42

Leroy, B. W., Walsh, P. N., & Rooney, M. (2004) Retreat and resilience. Life experiences of older women with intellectual disabilities. *American Journal on Mental Retardation, 109*(5) 429-441.

Lowe, K., de Paiva, S., & Felce, D. (1993). Effects of a community-based service on adaptive and maladaptive behaviour: a longitudinal study. *Journal of Intellectual Disability Research, 37,* 3-22.

Lund, R. Modvig, J., Due, P. & Holstein, B. E. (2000). Stability and change in structural social relations as predictor of mortality among elderly women and men. *European Journal of Epidemiology, 16,* 1087-1097.

Lynch, P.S., Kellow, J.T., & Willson, V.L. (1997). The impact of deinstutionalization on the adaptive behaviour of adults with mental retardation: a research synthesis. *Education and Training in Mental Retardation and Developmental Disabilities, 32,* 255-261.

Maisto, A.A., & Hughes, E. (1995). Adaptation to group home living for adults with mental retardation as a function of previous residental placement. *Journal of Intellectual Disability Research, 39,* 15-18.

Mansell, J. (1994) Specialized group homes for persons with severe or profound mental retardation and seriour behaviour problem in England. *Rersearch in Developmental Disabilities, 15,* 371-388.

Mansell, J., Felce, D., Jenkins, J., de Kock, U., & Toogood, S. (1987). *Developing staffed housing for people with mental handicaps,* Tunbridge Wells, England: Costello.

Marion, S. D., Touchette, P. E., & Sandman, C. A. (2003). Sequential analysis reveals a unique structure for self-injurious behavior. *American Journal on Mental Retardation, 108*(5), 301-313.

Marion, S. D., Touchette, P. E., Kroeker, R., & Sandman, C. A. (2005). Contagion and context: A response to Symons. *American Journal on Mental Retardation, 110*(4), 326-329.

McConkey, R., Walsh, P.N., & Conneally, S. (1993). Neighbours' reactions to community services: contrasts before and after services open in their locality. *Mental Handicap Research, 6,* 131-141.

McGill, P., & Toogood, S. (1993). Organising community placements. In E. Emerson, P. McGill and J. Mansell (Eds.) *Severe learning disabilities and challenging behaviours: designing high quality services.* London: Chapman & Hall.

McGill, P., Emerson, E., & Mansell, J. (1994). Individually designed residential provision for people with seriously challenging behaviours. In E. Emerson, P. McGill and J. Mansell (Eds.) *Severe learning disabilities and challenging behaviours: designing high quality services.* London: Chapman & Hall.

Molony, H., & Taplin, J.E. (1990). The deinstitutionalisation of people with a developmental disability under the Richmond program: changes in adaptive behaviour. *Australia and New Zealand Journal of Developmental Disabilities, 16(2), 149-159.*

Murphy, G., & Clare, I. (1991). MIETS: a service option for people with mild mental handicaps & challenging behaviour or psychiatric problems: 2 assessment treatment & outcome for service users & service effectiveness.

Murphy, G., Holland, A., Fowler, P., & Reep, J. (1991). MIETS: a service option for people with mild mental handicaps and challenging behaviour or psychiatric problems. *Mental Handicap Research, 4,* 41-66.

Nisbet, J., Clark, M., & Covett, S. (1991). Living it up! An analysis of research on community living. In L.H. Meyer, C.A. Peck & L.Brown (Eds.) *Critical issues in the lives of people with severe disabilities.* Baltimore: Paul H. Brookes.

Nord, G. B., Wieseler, N. A., & Hanson, R. H. (1998) The assessed crisis service needs of clients in community-based programs serving persons with developmental disabilities. *Behavioral Interventions, 13,* 169-179.

Nottestad, J. A., & Linaker, O. M. (1999) Psychiatric health needs and services before and after complete deinstitutionalisation of people with intellectual disability. *Journal of Intellectual Disability Research, 43*(6) 523-530.

Nottestad, J. A., Borge, S., & Olav, M. L. (1999) Psychiatric and behavioral disturbances in elderly mentally retarded before and after deinstitutionalisation. *Nordic Journal of Psychiatry, 54*(4) 281-286.

O'Brien, P., Thesing, A., Tuck, B., & Capie, A. (2001) Perceptions of change, advantage and quality of life for people with intellectual disability who left a long stay institution to live in the community. *Journal of Intellectual & Developmental Disability, 26*(1) 67-82.

O'Brien, J. (1994). Down stairs that are never your own: supporting people with developmental disabilities in their own homes. *Mental Retardation, 32,* 1-6.

O'Connor, B. V. (2001). *Social Role Valorization, social network transactions and life satisfaction for people with psychiatric disabilities.* Doctoral Dissertation. Ottawa: University of Ottawa.

Ontario Government (2004). *Ontario Government Improving Support for Ontarians with Developmental Disabilities: $110 Million To Strengthen Community Services And Close Institutions. Press Release issued September 9th, 2004.*http://www.mcss.gov.on.ca/CFCS/en/newsRoom/newsReleases/040909.htm

O'Neill, J., Brown, M., Gordon, W., & Schonhorn, R. (1985). The impact of deinstitutionalisation on activities and skills of severely/profoundly mentally retarded multiply-handicapped adults. *Applied Research in Mental Retardation, 6, 361-371.*

Parmenter, T. (1992). Quality of life of people with developmental disabilities. In N.W. Bray (Ed.) *International review of research in mental retardation.* New York: Academic Press.

Prouty, R., & Lakin, K.C. (2000). *Residential services for persons with developmental disabilities: status and trends through 1999.* Minneapolis: Research and Training Centre on Community Living, University of Minnesota.

Prouty, R., & Lakin, K.C. (1999). *Residential services for persons with developmental disabilities: status and trends through 1988.* Minneapolis: Research and Training Centre on Community Living, University of Minnesota.

Reid, D.H., Parsons, M.B., & Green, C.W. (1989). *Staff management in human services: behavioural research and application.* Springfield, Ill; Charles C. Thomas.

Repp, A.C., Felce, D., & de Kock, U. (1987). Obserational studies of staff working with mentally retarded persons: a review. *Research in Developmental Disabilities, 8,* 331-350.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., et al. (2001) Social networks of people with mental retardation in residential settings. *Mental Retardation, 39*(3) 201-214.

Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A. et al. Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation, 109*(4) 332-344.

Rose, K.C., White, J.A., Conroy, J., & Smith, D.M. (1993). following the course of a change: a study of adaptive and maladaptive behaviours in young adults living in the community. *Education and training in Mental Retardation, 28(2),* 149-154.

Rosen, D.B. (1985). *Differences in adaptive behaviour of institutionazed and deinstitutionalized mentally retarded adults.* Ann Arbor, MI: University of Microfilms International (DA8508127).

Rudolf, C., Lakin, K.C., Oslund, J.M., & Larson, W. (1998), Evaluation of outcomes and cost effectiveness of a community behavioural support and crisis response demonstration project. *Mental Retardation, 36(3),* 187-197.

Saxby, H., Thomas, M., Felce, D., & de Kock, U. (1986). The use of shops, cafés and public houses by severely and profoundly mentally handicapped adults. *British Journal on Mental Subnormality, 32,* 69-81.

Schroeder, S.R. & Hanes, C. (1978). Assessment of progress of institutionalized and deinstitutionalized retarded adults: a matched-control comparison. *Mental Retardation, 16,* 147-148.

Seys, D., & Duker, P. (1988). Effects of staff management on the quality of residential care for mentally retarded individuals. *American Journal on Mental Retardation, 93,* 290-299.

Shiell, A., Pettipher, C., Raynes, N., & Wright, K. (1993). A cost-function analysis of residential services for adults with learning disability. *Health Economics, 2,* 247-256.

Sinson, J.C. (1990). Micro-institutionalization? Environmental and managerial influences in ten living units for people with mental handicap. *British Journal of Mental Subnormality, 36,* 77-86.

Smith, D. (1981). *Obstacles: Report of the Special Committee On The Disabled And The Handicapped.* Ottawa: Ministry of Supply and Services Canada. (Also available at http://www.sdc.gc.ca/en/hip/odi/documents/obstacles/obstacles_full.pdf)

Smith, G. A. (2005, May 2nd). *Status Report: Litigation Concerning Home and Community Services for People With Disabilities.* Portland OR: Human Services Research Institute. http://www.hsri.org/docs/litigation050205.PDF

Spreat, S., & Conroy, J. W. (2002) The impact of deinstitutionalisation on family contact. *Research in Developmental Disabilities, 23,* 202-210.

Stancliffe, R.J., & Lakin, K.C. (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. *American Journal of Mental Retardation, 102(6),* 552-568.

Stancliffe, R. J., Hayden, M. F., Larson S. A., & Lakin, K. C. (2002) Longitudinal study on the adaptive and challenging behaviors of deinstitutionalized adults with mental retardation. *American Journal on Mental Retardation, 107*(4) 302-320.

Stancliffe, R.J., & Keane S. (2000) Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual & Developmental Disability, 25*(4) 281-305.

State of Wisonsin, Bureau of Evaluation, Division of Policy and Budget (1986), *Evaluation of the community integration program.* Madison, WI: Authors.

Strauss, D. Eyman, R. K., & Grossman, H. J. (1996) Predictors of mortality in children with severe mental retardation: The effect of placement. *American Journal of Public Health, 86*(10) 1422-1429

Strauss, D., Kastner, T. A. & Shavelle, R. (1998) Mortality of adults with developmental disabilities living in California Institution and community care, 1985-1994. *Mental Retardation, 36*(5) 360-371.

Symons, F. J. (2005) Readers' reaction: Self-injurious behavior and sequential analysis: Context matters. *American Journal on Mental Retardation, 110*(4) 323-326

Tabatabainia, M. M. (2003) Listening to families' views regarding institutionalization & deinstitutionalisation. *Journal of Intellectual & Developmental Disability, 28*(3) 241-259.

Taylor, S. J. (2001) The continuum and current controversies in the USA. *Journal of Intellectual & Developmental Disability, 26*(1) 15-33.

Thompson, T., & Carey, A. (1980). Structured normalization: intellectual and adaptive behaviour changes in a residential setting. *Mental Retardation, 18,* 193-197.

Tossebro, J. (1993). Background and prospects of institutional closure in Norway, Hester Adrian Research Centre Conference on Hospital Closure, University of Manchester, England.

Webb, O.J., Wells, J.E. & Hornblow, A.R. (1986). Institutions versus community placements: the effects of different residential environments on the behaviour of intellectually handicapped adults. *New Zealand Medical Journal, 99,* 951-954.

Williams, B.W., Paskow, F.S., Thoompson, L., & Levine, M.P. (1985). The effects of deinstitutionalisation on adaptive and maladaptive behaviours of a mentally retarded person. Unpublished.

Wente, M. (2005). When cruelty becomes official policy. *Toronto Globe and Mail* Tuesday, January 11, 2005, p.A17.

Widrick, G. C., Bramley, J. A., & Frawlwy, P. J. (1997) Psychopathology in adults with mental retardation before and after deinstitutionalisation. *Journal of Developmental and Physical Disabilities, 9*(3) 223-242.

Wolfensberger, W. (1972). *The principle of Normalization in human services.* Toronto: National Institute on Mental Retardation

Wolfensbeger, W. (1998). *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services.* (3rd ed., rev.) Syracuse, NY: Syracuse University, Training Institute for Human Service Planning, Leadership and Change Agentry.

Wolfensberger, W. (2003). *The Future of Children with Significant Impairments: What Parents Fear and Want, and What They and Others May Be Able to Do About It.* Syracuse, New York: Training Institute for Human Service Planning, Leadership & Change Agentry (Syracuse University).

Wolfensberger, W., & Glenn, L. (1975). *Program analysis of service systems: A method for the quantitative evaluation of human services* (3rd ed.). Vol. I: Handbook. Vol. II: Field manual. Toronto, ON: National Institute on Mental Retardation.

Wolfensberger, W., & Thomas, S. (1983). *PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals): Normalization criteria and ratings manual* (2nd ed.). Downsview, ON: National Institute on Mental Retardation.