

*i*nteraction

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Deinstitutionalisation:

• A Review of Literature

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• Lifestyle Supports

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Making Lives Real: Too Many Questions, Not Enough Action!

Meeting the individual supported-living needs of people with disability is not easy. The core questions are who is best placed to make decisions about how people with disability will be supported and, subsequently, who will have to bear the consequences of the decisions made?

Firstly, some thoughts on words and definitions. People with disability and their families frequently talk about their lives being seen as a whole. Ministers and government officials, however, divide people's lives into segments so that they can be easily administered — this does not reflect the real circumstances of how people live and, as a consequence, people's lives become artificial to suit bureaucratic rules.

Accommodation support and respite are two such artificially constructed segments. People with disability and their families prefer the term 'supported living'. For example, if someone receives in-home accommodation support or in-home respite what is the difference? From a bureaucratic point of view, the first is for the person with disability and the second is for their family but, from the whole family's point of view, this is an artificial division bordering on the ideological. It also means they have to go to different places/processes and, in some cases, to governments to get support, when the reality is that the support the person receives is exactly the same no matter what the name! This is but one example of how the lives of people with disability are not real lives but constructed lives (lives that bear no real resemblance to the lives lived by ministers and government officials).

So the question becomes: How can people with disability and their families have real lives and who should decide what is a real life?

The Commonwealth Government is currently consulting on the supported accommodation component of its Disability Assistance Package. Again, the Commonwealth Government has divided supported accommodation and respite into two totally separate components. On what basis and for whose benefit?

The discussion paper associated with the consultations has been described as a 'mess' and as 'chaotic'. The paper is confused, and anyone trying to fill it in will become *very* confused. Most of the 37 questions require detailed responses, yet the paper does not provide a framework to assist people to look at the questions and frame their answers within reasonable constraints.

Our primary questions are:

1. What is the legitimate role of governments? and
2. What do we know about the funding, purchasing and provision of support that delivers good lives – ie, outcomes which are flexible and provide quality supports?

The answer to the second question is already sitting on Minister Brough's desk. Disability Ministers commissioned the Social Policy Research Centre of the University of New South Wales to produce a report on: "Effectiveness of Supported Living in Relation to Shared Accommodation". Why is the information in this report not included in the discussion paper? Why has the report not been made available to assist people to make informed responses? Surely some, if not many of the questions that the discussion paper asks, will be answered by this evidence-based research!

This is not the only piece of research that the Government already has before it, which also includes *Interaction* Vol.19#3: “Presenting the Evidence”. Why haven’t the officials of the Department of Families, Community Services and Indigenous Affairs (FaCSIA) collated all the available research and presented it to inform the discussion paper?

How people spend their money is a matter for them. The Government though must spend taxpayers money in a manner that delivers good outcomes – they should not be driven by ideology but by evidence-based research.

It is important to reflect for a moment on the meaning of ideology:

i-de-ol-o-gy (n)

1. *a closely organised system of beliefs, values and ideas forming the basis of a social, economic or political philosophy/program.*
2. *a set of beliefs, values and opinions that shapes the way an individual or a group such as a social class thinks, acts and understands the world.*

The discussion paper is an ideological document and, as such, is deeply flawed. To ask people for their opinions, views or ideas without providing references to research and evidence that will inform the discussions that people will have is dishonest as it deceives people into thinking that all options will lead to a good life and/or that people will eventually get what they want. This is not the case.

The evidence is clear that, to meet the accommodation support needs of people with disability and where appropriate their families, people with disability must have control over what support they receive and how they receive it. Is there any other way? Are bureaucrats and politicians any better than people with disability and their families at deciding what support people should receive and how they receive it? In answering this question, we must remember who will bear the consequences of the decision! The concept of subsidiarity is important – ie, decisions should be made by those closest to the decision’s implementation.

To enable people to make decisions about their lives, there are a number of elements that must be in place:

1. Adequate funding – the Commonwealth’s commitment to meet the needs of all people with disability aged over 40 living with parents over 65 is welcome as it addresses the under-funding issue for this group and enables the other elements to be implemented.
2. Individualised funding based on assessment and banding of funding to meet support needs - the Commonwealth Government already implements this in its employment support program.
3. Option of self-managed funding - this is the third element to ensure that people with disability have control over their lives.

This brings us to the first of our primary questions: What is the legitimate role of governments in the funding, purchasing and provision of support services?

It is the role of the Commonwealth Government to ensure that people who need support receive it in an effective way. In spending taxpayer funds, it is reasonable for the Government to have:

1. eligibility criteria;
2. an assessment process that addresses the support needs of individuals;
3. an allocation of funds on an individual basis; and
4. simple accountability measures for ensuring that people get the support they need and that the funds allocated are spent by/on the individual concerned.

Beyond these, there are legitimate questions about the role of governments and hence what are the legitimate relationships. For example, should support providers have a contract with the government or with the person receiving a support? What are the costs (both financial and to people with disability) involved in the different contract relationships? What are the benefits in people with disability (and where appropriate their families) having control of their funds and hence entering into and negotiating the contracts they need for support. These are important questions and it is essential that FaCSIA and the Minister place any proposals before the Commonwealth Auditor General and the Office of Best Practice Regulation to have the costs and benefits of any proposals tested.

People with disability and their families urgently await the release of the “Effectiveness of Supported Living in Relation to Shared Accommodation” report and the deliberations of the Commonwealth Auditor General and the Office of Best Practice Regulation.

This issue of *Interaction* reviews positive lives for people with disability. In a major paper, the outcomes of deinstitutionalisation are reviewed and the positive changes that have occurred in the lives of many people with disability. The second paper looks at a range of models that provide good outcomes for people with disability. These show what is possible if people with disability and their families are given control to make their lives real!

FEEDBACK !

The Australian Institute on Intellectual Disability
would welcome feedback
(either as a Letter to the Editor or an article)
from readers, particularly people with disability and their families,
with their views/comments and experiences
regarding the important issue of
Accommodation for people with disability.

We look forward to hearing from.

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Deinstitutionalisation: A Review of Literature

by Belinda Epstein-Frisch
Family Advocacy (NSW)

Executive Summary

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, i.e., 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 people with disability 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, 1,720 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. The Department of Ageing, Disability & Home Care (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 NHS 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 NHS 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 service 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 through 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; Flynn: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, the 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 behaviour 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 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 disability 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

Scandinavian 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 deinstitutionalisation, 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 family member with a disability 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 the life of a person with disability 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 an 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 and Articles cited are available on request
or on website: www.ncid.org.au/aiid.htm*

LIFESTYLE SUPPORTS

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and
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This document provides a summary of selected examples of innovative approaches to lifestyle support for people with disability both within Australia and overseas.

Common elements of the approaches documented include:

- a strong value underpinning
- a focus on one person at a time
- most have a zero rejection: no-one is seen as too disabled with a ‘whatever it takes’ approach
- providing people with much more control over their homes and their lives
- a focus on relationships, using paid staff in a way that facilitates and supports opportunities for relationships
- a separation of housing and support
- most projects are small in size

The document was prepared to acknowledge and encourage creative thinking in the development of lifestyle supports that are based around meeting the needs of individuals. The intention is to move community thinking beyond more traditional service models in which support may be based around meeting the needs of groups of people solely on the basis of their disability and/or their support needs.

Many of the examples cited in this document have been sourced from a 2006 discussion paper commissioned by ACROD (now NDS) WA on behalf of the WA Innovation Think Tank (prepared by Deirdre Croft).

A summary of the featured options and their innovative dimensions is presented in the table below. A more detailed description of each option, in the words of the services themselves together with contact details, follows:

Model/Agency	Innovative Dimensions
<p>Individualised Options</p> <p>My Place (WA)</p>	<ul style="list-style-type: none"> • Focus on individual needs and wishes. • Individualised plans are dynamic working to extend the individual in progressing towards life goals. • Service Coordination (based on LAC model) assures strong community engagement and participation. • My Place Foundation operates as trust fund with Public Benevolent Status supporting resourcing flexibility.
<p>Family Care</p> <p>Perth Home Care Services (WA)</p>	<ul style="list-style-type: none"> • Supports adults who want on-going family-based care. • Only a small number of WA agencies provide alternative family care. (Perth Home Care Services is reportedly the largest provider).
<p>Co-Residency</p> <p>Lower Great Southern Community Living Association (WA)</p>	<ul style="list-style-type: none"> • Provides an alternative to shared care in group home option (i.e. more natural home-living environment). • Opportunity for one-to-one personal support relationship developing over time. • Provides for more spontaneous “normal” lifestyle which may include the “dignity of risk”. • Also incorporates a Community Development Program (based on inclusion principles and partnerships with mainstream service providers) as intrinsic to service.
<p>Co-Residency</p> <p>Vemvane (WA)</p>	<ul style="list-style-type: none"> • Co-residents are recruited as “flat-mates” and receive subsidized accommodation but no payment • Low cost option allowing on-site support and development of friendships while maximizing independence.
<p>Flexible, individualized Co-Residency</p> <p>Community Living Project (SA)</p>	<ul style="list-style-type: none"> • Supports people with high support needs, including people who have lived in an institution, to live in their own home with a co-resident • Intentional circle of support built around each individual to bring freely given relationships into the person’s life.

<p>Flexible, individualized Co-Residency</p> <p>Homes West (Qld)</p>	<ul style="list-style-type: none"> • Supports people with high support needs to live in their own home, most with a co-resident. • Care and support arrangements are shared between paid support and family and friends. Each individual has some funding which is used to compliment the support provided by people who give of their time freely.
<p>Mobile Attendant Care</p> <p>(Qld)</p>	<ul style="list-style-type: none"> • Provides personal care assistance between 6pm and 6am at scheduled times for pre-arranged service users and at unscheduled times when the service user calls for occasional or emergency support.
<p>Good Neighbour Program</p> <p>Midwest Community Living Association (WA)</p>	<ul style="list-style-type: none"> • Claimed to be the only program of its kind in WA. • Enables provision of support and independent living for people who would not qualify for critical needs accommodation support funding. Without the support of the good neighbour, participants in the program would be unable to leave the family home. • Strong partnership with local branch of Department of Housing and Works enables local development of innovative community-based options.
<p>Mutual support</p> <p>Key Ring (London, UK)</p>	<ul style="list-style-type: none"> • People with mild intellectual disability are supported to live in their own homes and be part of a network of mutual support. • A network of 9 people is supported by a community living worker who provides 10-12 hours of assistance to the network per week in exchange for free rent. • Emphasis on mutual support by the people with intellectual disability.
<p>Co-operative community</p> <p>Deohaeko (Toronto, Canada)</p>	<ul style="list-style-type: none"> • 7 people with intellectual disability and high support needs are supported to live in a co-operative community of 250 people. • Care and support arrangements are shared between paid support and family and friends. Each individual has some funding which is used to compliment the support provided by people who give of their time freely.

Agency: My Place

Contact	ph 08 6380 2927 myplacewa@bigpond.com.au
Website	www.myplace.org.au
Innovative Dimensions	<p>My Place focuses on individual needs and wishes (rather than a standard model) incorporating the following features:</p> <ul style="list-style-type: none">• Individualised plans are dynamic working to extend the individual in progressing towards life goals.• Service Coordination (based on LAC model) assures strong community engagement and participation.• My Place Foundation operates as trust fund with Public Benevolent Status supporting resourcing flexibility.
People Supported	<p>Supports approximately 120 people with a range of disabilities to live in the community. My Place consumers include people with intellectual disability, autism, cerebral palsy, multiple sclerosis, muscular dystrophy and spinal injury ranging in age from six years to 60 years. About 12 have no verbal means of communication.</p>
Model of Support	<p>Individualised options are based on personal choice including living in the person's own or family home with support, co-residency, host family and support for self managed funding. About 80% of consumers are supported to live in their own home (renting, purchasing or the family home). The remaining 20%, typically younger people, are supported to live in co-residency arrangements or with a host family.</p>
Key Principles	<p>Key operating principles are based on:</p> <ul style="list-style-type: none">• a Focus on the individuality of the person and person-centred planning i.e. "My Place", "My Plan".• personal choice and control over how the person lives his or her life.• extension of abilities and life choices working to life goals.• encouragement, opportunities and support for personal and educational development and community and economic participation.

Key Features

Funds are held in trust in the My Place Foundation which operates as a Public Benevolent Institution. The flat management structure minimizes administrative expenses enabling maximum direct care funds to be spent on services for the individual.

Service Coordinators at My Place work like Local Areas Coordinators (LACs) coordinating and managing service supports. By establishing a personalized on-going relationship with a clearly defined consumer group, Service Coordinators provide a fixed point of accountability, expertise and advocacy on individual needs and links with local communities. Service Coordinators supervise the work of direct care staff.

Each person is supported to develop their own plan “My Plan” which outlines their goals in life and how these may be achieved. In consultation with the consumer and, where appropriate, his or her family, the plan is updated regularly.

The office premises in Subiaco include spacious meeting rooms which are also used for community activities organized for or by My Place consumers.

Background

My Place was established by Mr Peter Dunn, Dr Gregory Lewis and Dr Phillip Deschamp in 1996 in response to a perceived need for more flexible and individualized approach to provision of support. In 1987, Dr Lewis established the ground-breaking Local Area Coordination program which now has statewide coverage. Peter Dunn was the first Local Area Coordinator in the Lower Great Southern Region. Dr Deschamp has served on the Boards of the former Authority for Intellectually Handicapped Persons and the Disability Services Commission.

My Place has grown rapidly in recent years (from supporting 30 people in 2000 to 120 people at the end of 2004).

People Providing Support

My Place employs 160 support workers – called Personal Assistants – to provide direct care support under the supervision of the responsible Service Coordinator.

In host family or co-residency arrangements (accessed by about 20% of consumers), the person with disability becomes part of the extended family. The aim is to build a relationship based on give and take (rather than dependency) with the goal of moving to greater independence for the person with a disability.

Service Coordinators oversee all the direct care and support arrangements.

Agency Support Provided	<p>My Place supports the development of options, application for and management of funding, recruitment, training and payment of direct care staff.</p> <p>My Place will also support people who wish to manage their own funds and thereby increase resourcing available for direct care. About 7 people have been supported to establish micro agencies under the auspices of My Place to enable direct management of funding in this way.</p>
Benefits	<p>The individualized approach offers flexibility, and increased personal choice and consumer control.</p>
Challenges	<p>Current challenges include the management and resourcing of changing needs particularly for consumers with degenerative conditions who may require increasing medical support.</p>
Sustainability	<p>The development and expansion of My Place reflects the commitment and dedication of the three founding directors. Succession planning is underway to assure maintenance of the vision and approach beyond the working life of the key players.</p>
Future Directions	<p>A decision has been made to maintain the agency at its existing size to ensure that the personalized nature of service provision, in which Service Coordinators have a direct voice and input, can be maintained.</p>

Agency: Perth Home Care Services

Contact Website	Marita Walker CEO maritaw@phcs.org.au Perth Home Care Services: http://www.phcs.org.au/
Innovative Dimensions	Alternative family care options service a niche market meeting a unique need for adults who require and will benefit from on-going family-based care. Only a small number of WA agencies provide alternative family care. (Perth Home Care Services is reportedly the largest provider.)
People Supported	Perth Home Care supports 15 people with multiple needs ranging in age from 18 to late 50s who may benefit from more personalized family-based care. A number of those supported have been relocated from institutional care or graduated from wardship under the Department for Community Development. Perth Home Care Services does not consider the Family Care Option it provides to be suitable to people with challenging behaviours.
Model of Support	Under the Alternative Family Care model (i.e. Family Based Foster Care for Adults), the person with disability becomes part of the family and participates in normal family life. Perth Home Care Services also offers a range of other individualized accommodation support options.
Key Principles	Alternate Family Care is based on: <ul style="list-style-type: none"> • providing personalised care in family environment • promoting natural family and community connections.
Key Features	<p>The person with disability becomes part of and participates in the life of the family.</p> <p>A respite component is built in (from 2-8 days/month plus 4-5 weeks per annum). Respite takes place at the home of another family specially recruited for this purpose. Other respite options may also be utilized.</p> <p>A carer reimbursement (not a salary) is negotiated with the alternative family carer depending on the level of the support needed by the person with a disability and may range from \$180/week up to \$700/week. The alternative family carer is not “employed” as such and is not therefore covered for workers’ compensation or superannuation entitlements.</p> <p>A written agreement spells out the responsibilities of both the carer and the agency (including provision for regular review).</p> <p>The alternative family carer has access to specialist and professional services if required.</p>

Background

Perth Home Care Services was established in 1967 initially as an emergency housekeeping service to provide short-term assistance to families in the event of hospitalization, illness etc. In 1985, funding through the Home and Community Care Program signaled a change of direction with an emphasis on services to enable frail elderly people and people with disability to remain in their own home. The first Alternative Family Care options were established in the early 90's for a number of residents moving from larger-scale residential care. In 2006-07, Perth Home Care Services reported that it was supporting a total of 1,500 people in the community (including those in Alternative Family Care) with 579 staff providing 378,574 hours of service.

People Providing Support

Alternative family carers come from a variety of backgrounds including single people and families with children. Most alternative family carers have prior exposure to the disability field and many have a pre-existing relationship with the person with a disability e.g. staff from Pyrron and Bristol Hostel, or as foster parents in a wardship arrangement which has now moved into guardianship. There are a number of alternative family care arrangements in the Northam, Toodyay, York area which means the local community is familiar with the concept if additional recruitment is required. For each alternative family carer, a respite family/ies is also recruited.

Agency Support Provided

Perth Home Care supports links to specialist services and community access opportunities.

A Service Coordinator maintains regular contact (at least every three months).

Benefits

Support is based on the establishment of a caring personal relationship. The person with a disability is linked into family networks with the opportunity to experience normal family life.

Challenges

Current challenges include:

- the interface between wardship responsibilities of the Department for Community Development, adult guardianship arrangements and Disability Service Commission responsibility for accommodation support funding.
- Carer reimbursements which may have implications for family carers who also receive Centrelink payments.
- the small pool of potential family carers available.

Sustainability

The longest arrangement has been in place for 12 years.

The level and nature of support required is a significant factor in the longevity of the arrangement.

Agency: Lower Great Southern Community Living Association

Contact	<p>Kathy Hough Executive Officer for Lower Great Southern Community Living Association as well as a co-resident (as of the past 12 years) with a now 50 year old woman with an intellectual disability. lgscla@inet.net.au</p>
Innovative Dimensions	<p>The co-residency option offered through Lower Great Southern Community Living Association (LGSCLA) provides:</p> <ul style="list-style-type: none"> • an alternative to shared care in group home option with rostered shifts of support workers and potentially incompatible fellow residents (i.e. more natural home-living environment). • an opportunity for one-to-one personal support relationship developing over time. • for a more spontaneous “normal” lifestyle which may include the “dignity of risk”. <p>A Community Development Program (based on inclusion principles and partnerships with mainstream service providers) is intrinsic to the service provided through LGSCSA.</p>
People Supported	<p>Eleven people of varying disabilities and needs ranging in age from 18 years to 67 years are currently supported in co-residency arrangements. An additional 15 people are supported through other individualized options. Most have an intellectual or cognitive disability.</p> <p>As a member of the Disability Services Commission’s Challenging Behaviours Consortium, LGSCLA also has the capacity to support people with challenging behaviours.</p>
Model of Support	<p>Co-residency is based on the person with a disability sharing premises with another person who provides needed support.</p>
Key Principles	<p>The model is based on creating the most natural context in which people can be supported in a home environment with a strong focus on community inclusion and participation.</p>

Key Features

The person with a disability and person providing support reside in same rental premises and share living expenses. To assure security of tenure, the lease is held by the person with a disability.

The co-resident is paid a wage including salary packaging for the care provided (usually with one day off/week plus respite available every second weekend and four weeks annual leave).

The person with disability participates in day activities (which also provides day-time respite for co-resident) and other community activities based on holistic approach to person's needs.

Background

Lower Great Southern Community Living Association (LGSCLA) was incorporated in 1991 on the initiative of the then Local Area Coordinator who continued to play an active part until 1994.

The agency initially established a co-residency arrangement for two women who had very different lifestyles (one being relocated from large Perth-based institutional care, the other moving from the local family farm). It became apparent that more individualized arrangements were required.

Since 1997, LGSCLA has also been accredited by the Disability Services Commission as a service provider for Alternatives to Employment with substantial growth over the past 8-9 years.

People Providing Support

Co-residents come from a range of backgrounds (including students, mature age women, young couples). Most have some personal or professional connection with disability.

Personal networks are considered a more effective recruitment strategy than advertising.

Agency Support Provided

Management support is through the Executive Officer and three Coordinators with 24 hour back-up for support workers.

Networking and training is provided on how to respond to caring demands including self-care.

A Community Development Officer is employed to support inclusion in mainstream community activities (e.g. in TAFE lifestyle courses, Safety First Training, Consumer Awareness and Protection Courses)

Benefits

Co-residency is considered to provide many benefits including the:

- development of close personal relationship between the person with disability and co-resident.
- opportunity for spontaneity in lifestyle in normal home environment.
- community connections through the cohesive local community.

Challenges	<p>Operational challenges include:</p> <ul style="list-style-type: none"> • determining who leaves the home during respite and holiday periods. • managing the process of transition when the existing support worker wishes to move on. • responding to the level of demand – there is wait list for service support.
Sustainability	<p>The average turn-over of co-residents is 3 to 5 years. Longer-term arrangements have existed for 8-12 years. Most former co-residents maintain contact beyond their direct caring relationship period. However, a process of personal grieving and adjustment is acknowledged.</p>
Future Directions	<p>Following a recent family meeting on how to develop more cost effective options, consideration is being given to the expansion of the co-residency concept in which two people with a disability may be supported by a co-resident particularly where there is a pre-existing friendship/relationship between the people and/or compatibility is assured.</p>
Local Factors	<p>Strong community cohesion and spirit in Lower Great Southern regional WA.</p>

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Agency: Vemvane

Contact	<p>Contact: Michael Schweiger Ph: 08 9307 5420</p>
Innovative Dimensions	<p>Vemvane (a Zulu term that describes the transformation of a caterpillar to a butterfly) has supported a co-residency arrangement over the past ten years for a now 35 year old man with a moderate intellectual disability.</p> <p>Vemvane is a small agency based in the outer northern metropolitan area which receives minimal Disability Services Commission funding and draws extensively on support that is “freely given”.</p>
Model of Support	<p>With agency-subsidized rental accommodation for a three-bedroom apartment in Northbridge (within easy walking distance of all amenities and including on-site access to a swimming pool and gym), two co-residents were initially recruited through normal advertising for “flat-mates”. Only upon application are they advised of the particular additional support requirements of their co-resident. It should be noted that, for the last eight years, all co-residents have been recruited through the social networks that have evolved in this situation, negating the need for public advertising. While no formal qualifications are required, the co-residents are required to enter into an agreement on support expectations which may also include the opportunity for access to their own social networks. In return, they receive a rental subsidy and a contribution to their shared living costs. Each resident currently pays \$85/week for full board and lodgings. One of the current co-residents is in a rock band and recently invited his flat mate to join him in a national tour on the basis that he considered him to “be part of the band”.</p> <p>Two paid support workers provide an occasional visiting service while a coordinator maintains oversight of the service. The total agency cost to provide the service is between \$12,000 - \$14,000/year.</p>
People Supported	<p>The current co-residents are a male aged 30 years and a female aged 27 who have participated in the co-residency support arrangement for three years and one year respectively. Both current co-residents were recruited through existing social networks. Several previous co-residents have participated for more than a four-year period and the majority still maintain contact through the established social networks. As the support arrangement has evolved, recruitment of new co-residents has typically been through a departing resident’s networks.</p> <p>In addition to this arrangement, Vemvane also provides independent living support to one other client member.</p> <p>Other Vemvane services include respite (under the banner of providing a break from everyday routines for the person with disability), day activities and advocacy. Vemvane has a client member base of 35 people most of whom have an intellectual or developmental disability ranging in age from nine years to 55 years. The agency is supported by family members, friends and their networks. With total Disability Services Commission funding of \$295,000/year, the majority of assistance provided is “freely given”.</p>

Agency: Community Living Project (CLP)

Contact	phone: (08) 8384 7866 info@clp-sa.org.au
Website	www.clp-sa.org.au
Innovative Dimensions	<p>People with intellectual disability, many of whom have very high support needs, live in their own homes in their communities with an active lifestyle similar to people without disability.</p> <p>Intentional circles of support have been built around some individuals to bring freely-given relationships in the person's life.</p>
People Supported	35 people are supported, 15 of whom have very high support needs. 25 live in their own homes and 10 continue to live in the family home..
Model of Support	Some people live alone and others share their home with a partner, a friend, a lover or boarder. Some live with their families.
Key Principles	<p>Home: Home is seen as much more than a house, as a unique environment that gives the person a sense of security, pride, privacy and retreat.</p> <p>Relationships: Recognition that people with intellectual disability may need assistance with the complexities of developing and nurturing relationships means that CLP support helps people to sustain existing relationships while also taking the opportunity to build new relationships.</p> <p>Valued roles: (roles that have a status in the eyes of others) CLP strongly believes that with some thoughtfulness about a person's gifts and talents, some careful planning, and with a creative, diligent effort, the CLP can nurture opportunities for any person to move into roles that are afforded a higher status, and subsequently the person concerned is seen as more highly valued in the community.</p> <p>Competencies: CLP believes that everybody has the capacity to learn new things, particularly if the things being learnt have relevance to the person concerned. CLP recognizes that positive expectations, a confident attitude, access to great role models, creativity in teaching processes and having realistic goals, all contribute to and enhance chances for ongoing growth and development.</p> <p>Community Participation and Inclusion: CLP believes that inclusion means being supported to be part of, and contribute to, and be involved in all the same activities, at the same places and right beside all other community members.</p>

Key Features	<p>CLP is managed by a Board of Directors that delegate authority to the Executive Officer.</p> <p>CLP uses part-time co-ordinators to coordinate the supports for individuals. Each person's support is developed in conjunction with them and their network so as to reflect their own aspirations. People play a primary role in selecting their own staff and determining the roles that those people will play.</p> <p>CLP delegates authority to three people with disability and their families to entirely manage their own supports. In this situation, the CLP assists in the fulfillment of responsibilities of employer.</p>
Background	<p>The Community Living Project (CLP) incorporated in 1985 because of the leadership shown by a small group of parents in the southern region of Adelaide who banded together as the Parents of Disabled. They desperately wanted a service that would support their son or daughter with an intellectual disability and/or multiple disability to continue living in their local community in adulthood. They wanted a service that would secure a lifestyle and future for their son/daughter which was like those of other family members. They also wanted to feel reassured that their lifestyle would continue when they were no longer around.</p> <p>At the time, no such service existed – hence these parents worked tirelessly to create the CLP.</p>
People Providing Support	<p>CLP employs 33 support workers.</p>
Agency Support Provided	<p>CLP is an incorporated association with a Board of Management, a CEO, coordinators and support workers.</p> <p>CLP provides support to people in their own home and also supports 10 people living in their family home.</p>
Benefits	<p>The individualised approach offers flexibility, and increased personal choice and consumer control.</p>

Agency: Homes West

Contact Website	07 3278 2378 helend@homeswest.org.au www.homeswest.org.au
Innovative Dimensions	<p>Homes West supports 12 individuals with disability, some with high support needs.</p> <p>Family, community and government resources are harnessed to embed adults with disability in their communities.</p> <p>The care and support arrangements are shared between paid support and family and friends. Each individual has some funding which is used to compliment the support provided by people who give of their time freely. The families work as a collective to support each other to develop a home for each of their sons and daughters and a full and active life in their community.</p>
People Supported	12 people with disability and high support needs.
Model of Support	Each person lives in his/her own home. Many share their homes with people without disability.
Key Principles	<p>People with disability are entitled to a lifestyle which is based on the same rights and opportunities as other citizens, regardless of type or degree of disability.</p> <p>Regardless of capacity or skill, families have a natural authority and are entitled to influence the direction of their son's or daughter's life.</p> <p>A home is much more than 'bricks and mortar' – it should enhance a person's personal privacy and security, the development of relationships and intimacy, and the expression of individuality through flexibility and choice.</p> <p>Community inclusion is much more than living in a house in the suburbs. It gives rise to active and meaningful participation in community life and the development of broader networks.</p> <p>Families, community and paid service providers can work together in respectful, 'right' relationships to support a person with disability to live his or her life well.</p> <p>Families do best when they work co-operatively together, sharing their skills, experiences and capacities. With collaboration comes a synergy – the whole is greater than the sum of the parts.</p>

Key Principles (Cont'd)

Homes West families assume:

- families want continuing involvement and relationship with the person with disability;
- families already have some established networks on which they can build;
- a person with disability will continue to grow, learn and change throughout his/her life;
- parents are likely to die before their children;
- little that is worthwhile happens without planning and thought;
- funding will not be available to meet every person's support needs;
- people who have services dominating their lives are in danger of losing connections with family and friends, and with others who would freely give their time, energy and commitment. The larger and more traditional the service, the more likely this will happen.

Key Features

The service is family governed with a collective of families assisting each other to plan for the life of each individual.

There is a clear differentiation between 'family business' and 'service business' in relation to each individual and 'Homes West or organisation business'.

Family business:

- develops a positive vision for their family member and themselves and to plan for the future;
- establishes the values and standards for their family member's future life, and to safeguard his/her privacy and integrity;
- helps the person to decide what is negotiable and acceptable within the family's culture, beliefs and traditions; and
- directs the level and type of service the person needs.

Service business:

- builds on and supports what networks are naturally there;
- protects the person and their family from intrusive bureaucratic processes;
- provides accountability for the expenditure of funds;
- employs, trains and supports staff; and
- supports and encourages the families for the long term to do their best.

Homes West business:

- brings families together to govern and direct the business of Homes West to ensure the service does the best for people;

Key Features (Cont'd)

- allows families to make the hard decisions – what is non-negotiable, when to compromise, what is possible and what just can't be done;
- nurtures the spirit, and maintains a willingness to come together to work for the common good of the families; and
- reaches out to the broader community to place Homes West as an organisation and to find supporters and future leadership.

The day-to-day management is accomplished by a management committee.

Major decisions and initiatives are addressed at the quarterly family meetings.

Homes West employs one co-ordinator and approx 50 support staff.

Each Homes West person has his/her own team of part-time workers undertaking specific roles with that person. Each worker supports only one person.

A common process is used by most families but Homes West has no standard model of service.

Right relationships govern Homes West's approach to family business, service business and Homes West business.

Background

Homes West was started by a group of parents of people with disability in 1990. The organisation gained one-off funding from the Qld. Government in 1993. By 1996, it had made a long-term commitment to 10 people with disability and their families. They were guided by the Community Resource Unit to work out their core beliefs and assumptions and develop its practice.

Homes West supports families through four phases so that their son or daughter with disability can plan a lifestyle, establish a home of their own, feel anchored in their community and be safe and secure when their parents are no longer around.

People Providing Support

The planning for each person with disability is undertaken by family and informal support networks supported by a paid facilitator.

50 part-time support staff, working in teams (one for each person) who undertake specific roles for each person.

Agency Support Provided

Homes West is a parent organisation established specifically for the purpose of supporting 12 people with disability to establish homes of their own and to build rich and full lives in their community.

Benefits

Each person with disability has a home of their own and their own lifestyle, even without full government funding.

Each person is firmly embedded in the community through relationships with people who care about the person and seek to spend time with the person.

Sustainability

Families and Homes West are continually focused on bringing in new people to sustain the network around the person with disability and developing a succession plan for each family and for the organisation as a whole.

Agency: Mobile Attendant Care (MAC)

Contact	07 3356 8808 macs@st.net.au
Website	www.macsinc.org.au
Innovative Dimensions	Provides personal care assistance between 6pm and 6am at scheduled times for pre-arranged service users and at unscheduled times when the service user calls in for occasional / emergency support.
People Supported	People with physical disability who need assistance with personal care. The number of scheduled visits by MAC attendants is approx 38 every night of the year with up to 6 call-ins and Vita-calls in addition to regular visits per night (2002). The delivery of the service is across 25 suburbs with each of the 4 attendants driving between 80 and 100 kms/night
Model of Support	Some service users have pre-arranged times for assistance. Others use the service for occasional or emergency support. Attendants drive to the home of service users to provide support.
Key Principles	MAC is based on <ul style="list-style-type: none">• a sound values base about respecting human worth and integrity and valuing diversity;• a commitment to creating service arrangements that allow people with disability to shape how the service is provided;• the importance of people knowing one another, remaining small and operating in a non-bureaucratic way;• leaving personal lifestyle decisions to the realms of each individual service user;• Using open, personalized and flexible approaches to assistance;• holding a shared vision and understanding of good practice, with good relationships and skills to do what is required.
Key Features	Attendant carers drive from home to home providing planned, occasional and emergency personal care assistance between 6pm and 6am. Service users are involved in the development, planning and management of their own support and of MAC.

Background	MAC commenced in 1992 in response to a need within the area for a service which provided night-time assistance. Service user involvement from a service development, planning, management and review perspective is historically an integral part of MACS. The original objective of “by the people for the people” continues to underpin the service that has grown and developed in response to changing needs and the changing climate of service provision.
People Providing Support	Trained attendant carers.
Agency Support Provided	MAC is a small non government agency operating in 25 suburbs of Brisbane
Benefits	People can lead the lifestyle they wish, coming home when they wish. Assistance is available for emergencies.
Sustainability	MAC has grown from strength to strength receiving very positive evaluations.

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Agency: Midwest Community Living Association

Contact	Angie Godden mwcla@bigpond.com 08 9921 1505
Innovative Dimensions	<p>The program enables provision of support and independent living for people who would not qualify for critical needs accommodation support funding. Without the support of the good neighbour, participants in the program would be unable to leave the family home.</p> <p>A strong partnership with the local branch of Department of Housing and Works enables local development of innovative community-based options.</p>
People Supported	The good neighbour program currently supports one person with an intellectual disability and two people with mild cerebral palsy. None of the people participating in the program receives accommodation support funding.
Model of Support	Support is provided by a neighbour living in adjoining unit. (MidWest Community Living Association also supports people through other individualised models, such as co-residency).
Key Principles	The model builds on natural community connections and spirit of neighbourhood support.
Key Features	<p>Sets of adjoining units are provided through the Department of Housing and Works. The units are adapted to meet any special access or aid requirements of the residents.</p> <p>One unit is allocated to the person/people with disability. The adjoining unit is allocated to a person/family who agrees to perform the role of a “good neighbour”</p> <p>Agreement to participate in the program ensures priority access to quality accommodation for which the good neighbour might not otherwise be considered on a priority needs basis. Good neighbours also become eligible for rent assistance through Centrelink.</p> <p>Both the person with disability and the good neighbour are responsible for their own living expenses, including rent which is charged as 25% of total income. The support required is negotiated informally between the two sets of neighbours and the family of the person with disability and documented in a written agreement. Support may include help with domestic (cooking, cleaning, etc.) and/or support for independent living e.g. transport, reading and explaining mail, being a friend or someone to contact in case of an emergency.</p>

Key Features (Cont'd)	<p>The initial planning also includes contingency arrangements for occasions when the good neighbour may be absent for any length of time, and back-up support in emergency situations.</p> <p>The level of support required usually diminishes over time as the person with disability achieves greater competence and/or independence.</p>
Background	<p>Midwest Community Living Association was started by two local parents and the Local Area Coordinator in 1990. Since then, it has operated on a voluntary basis with three unpaid coordinators and a small group of dedicated parents.</p>
People Providing Support	<p>Good neighbours come from a range of backgrounds but must be eligible for community housing through the Department of Housing and Works, i.e. people on a low income. Many have been located by the person with disability or their family and friends.</p>
Agency Support Provided	<p>The agency oversees the advertising and recruitment of “good neighbours”.</p> <p>In consultation with all parties, the program Coordinator oversees the initial planning of the arrangement and documentation of the written agreement which is updated regularly.</p> <p>The Coordinator maintains regular contact through visits and telephone calls and mediates if any issues arise. Ongoing support is also provided to families in adjusting to their family member living away from home.</p> <p>Rents are collected by the agency usually through automatic deduction from Centrelink benefit or wages.</p>
Benefits	<p>The model offers localised, community-based support with an opportunity for independent living not otherwise available through a funded model.</p>
Challenges	<p>At a service level, potential challenges are identified in advance (with contingency plans set in place) and monitored through the regular review process.</p> <p>At a program level, an additional five local people with disability have indicated they would like to participate in the program pending the allocation of additional housing through the Community Housing Program of the Department of Housing and Works.</p>
Sustainability	<p>The longest arrangement has been in existence for eleven years, during which time three different “good neighbours” have provided support – all the new neighbours were located by the tenants and/or their family or friends. The third arrangement has been in place for the past two years with the same good neighbour throughout.</p>

**Future
Directions**

Midwest Community Living has recently taken on management of a support package for a person with challenging behaviours who has received accommodation support funding through the Disability Services Commission. With the support of the local office of the Department of Housing and Works, the person with disability and their "live-in" carer have been allocated duplex accommodation enabling each to have their own independent living space on either side of the premises.

The agency's new role in managing DSC support funding will enable access to housing options that are tied to the availability of support packages and expand the capacity to meet local needs.

*** SPECIAL ***

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Agency: KeyRing

Contact	enquiries@keyring.org
Website	www.keyring.org
Innovative Dimensions	<p>People with mild intellectual disability are supported to live in their own homes and be part of a network of mutual support.</p> <p>The network (with a max of 9 people) is supported by a community living worker who provides 10-12 hours of assistance to the network per week in exchange for free rent.</p> <p>Emphasis on mutual support by the people with intellectual disability.</p>
People Supported	<p>People with mild intellectual disability who have basic self-care skills but need either continuing or intermittent support. 35% of KeyRing tenants have lived in some form of shared housing (group homes) prior to joining KeyRing. 42% previously lived with family. Most of the remaining tenants had formerly struggled without formal support, including some who had become homeless.</p>
Model of Support	<p>KeyRing services are based on the idea of ‘living support networks’. Small networks of up to 9 people with low support needs are established in a particular neighbourhood using ordinary social housing. Each individual has his or her own flat, all within walking distance of each other.</p> <p>A community living worker is appointed and, in return for free accommodation, commits an average of 10-12 hours per week to assist members of the network. The community living worker lives as part of the network in the same neighbourhood as the KeyRing tenants.</p>
Key Principles	<p>Enabling people with mild intellectual disability to get and maintain a home of their own.</p> <p>KeyRing is based on the acceptance that the service cannot control the lives of the tenants – support can be offered and negotiated but not imposed.</p>
Key Features	<p>The development of mutual support among members of the living support network.</p> <p>Partnership between the local housing department, the social service department and KeyRing.</p> <p>The living support worker assists tenants in dealing with the official world, helping them budget and helping them to access other services as needed.</p>
People Providing Support	<p>Living support workers do not have any particular qualifications.</p>

Agency: Deohaeko Support Network

Contact	janet@legacies.ca
Innovative Dimensions	<p>Deohaeko enables 7 people with disability to live in a co-operative community (called Rougemount) in Ontario, Canada. The co-op is home to approx 250 people representing the typical mix of singles, families and single parents living in 100 one, two or three-bedroom apartments.</p> <p>Care and support arrangements are shared between paid support and family and friends. Each individual has some funding which is used to compliment the support provided by people who give of their time freely.</p>
People Supported	<p>Supports 7 people with a significant disability (some of whom need 24-hour support) to live as part of the housing co-operative.</p>
Model of Support	<p>People live in their own 1 or 2 bedroom apartments, each with their own personal support network made up of family, friends, neighbours and personal supporters.</p> <p>Deohaeko deliberately fosters a spirit of mutual neighbourhood support to develop an intentional community in which everyone is seen as having gifts and contributions.</p>
Key Principles	<p>Key operating principles include:</p> <ul style="list-style-type: none"> ○ The value and uniqueness of the individual ○ valuing community ○ overarching importance of relationships ○ supportive decision making ○ setting standards about age and gender appropriate roles to make a complete day and a valued life ○ Gathering with allies to do the work ○ learning to listen ○ celebrating everything
Key Features	<p>Deohaeko Support Network (DSN) made a conscious decision to support only a small number of people to live in a cooperative community.</p> <p>The families of the 7 people who live in Rougemount make up the Board (family governed) and support each other to make decisions about their family member.</p> <p>Each family hires the people who assist their family member.</p>

Key Features (Cont'd)	<p>The co-ordinator works for DSN as a whole, as well as for individuals and their family. She helps set the vision and assists families deal with times of transition and change. She meets regularly with each person being supported, either weekly or daily depending on need.</p> <p>DSN sees its role as overseer of the support provided to each individual including: ensuring quality day-to-day, planning for and recognizing opportunities for new relationships, providing a home that is safe and secure, unique, individual and welcoming to others, ensuring a community presence which is legitimate and valued, occurring on a frequent and regular basis.</p>
Background	<p>Deohaeko is a small group of families who came together in 1988 in Toronto, Canada to develop support for their sons and daughters with disability. They received a government grant to design and build a housing co-operative, Rougemont, which became a 6 storey 100-unit housing co-operative. The families did not want a residential service for their sons and daughters with disability. They were looking to develop an intentional community in which people with disability would live with people without disability. Rougemont became the 'where'. The Deohaeko Support Network became the 'how' – a Board of families who employ paid workers to work individually with each person with disability, some of whom require 24-hour support.</p>
People Providing Support	<p>Each person being supported has his/ her own support network, made up of family, friends, neighbours and personal assistants. The coordinator assists the family to recruit, direct and supervise the personal assistants.</p>
Agency Support Provided	<p>Deohaeko Support Network is an incorporated association under a Board of Management made up of the families. Deohaeko makes all decisions about allocating all funds received by the families from government according to the support plans for the individuals.</p>
Benefits	<p>The people have very rich lives included in a large intentional community of people committed to neighbourly support.</p>
Challenges	<ul style="list-style-type: none"> • Ensuring quality support day to day • Recognizing and seizing new opportunities for new relationships • Future funding • Board membership • Supporting and nurturing the support network • Starting over again with each new supporter
Sustainability	<p>Succession planning is underway to assure maintenance of the vision and approach beyond the working life of the key players.</p>
Future	<p>DSN has committed to remain focused on the 6 people with disability it currently supports. It provides presentations to support other families.</p>

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