# Challenging Institutions

## Community Living for People With Ongoing Needs
## A Coalition Against Segregated Living Publication

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## 1. OVERVIEW

*Human Rights are universal, and civil, political, economic, social and cultural rights belong to all human beings, including differently-abled persons. Differently-abled persons are entitled to the realisation of all human rights and fundamental freedoms on equal terms with others in society, without discrimination of any kind. They also enjoy certain human rights specifically linked to their status*

*(Human Rights and the Differently Abled, United Nations 1999)*

All people with disabilities have the right to be fully integrated into all aspects of community life. This in accordance with Australia's international obligations – in particular our adherence to the United Nations Standard Rules which state a number of pre-requisites for equal opportunity. The most important requirement is the provision of support services that are community-based and that allow people with disabilities to live in and be part of the community.

Over the past thirty years there has been an international movement away from confining people with intellectual disabilities in institutions. As a result institutional closures in countries such as United States, Canada, England and Australia have slowly but steadily gained momentum. The movement has grown out of the belief that the practice of congregating and segregating people from the general community is not only a violation of human rights but also leads to an extremely poor quality of life.

Recently in Victoria a report detailing the movement of a group of men from a large congregate care facility to community living painted *a compelling picture of the enhanced living skills, community participation, family contact, independence and personal competence of these men following their move and the decline in their challenging behaviours. Written by independent consultants the report is a glowing endorsement of the policy to relocate people from the outmoded institutional confinement of Kew Residential Services.* (Hon. Denis Napthine MP former Victorian Minister for Youth and Community

Services in correspondence to AMIDA, about the Hirondelle Report 16/9/1999)

However, there continues to be some sections of government and the community maintaining that community living is not the optimum option for all people with an intellectual disability particularly those with severe or multiple disabilities or those labelled as having challenging behaviours. As a result, in Australia and overseas the redevelopment of older institutions and the development cluster housing estates has occurred.

The organisation *Action for More Independence and Dignity in Accommodation* (AMIDA) in conjunction with the *Coalition Against Segregated Living* (CASL) undertook the research documented in this report in order to show that the universal right of community living can be realised for all people regardless of their degree of disability. The following report documents:

- the detrimental effects of living in congregated and segregated accommodation such as institutions, cluster housing estates and redeveloped facilities.
- Australian and overseas community living services which demonstrate that community living is achievable for all individuals regardless of their level of disability and that moving to community based housing from an institution significantly improves a person's quality of life.
- accommodation, service delivery methodologies and behaviour support models, used to support people with ongoing needs living in the community.

## 2. PROJECT HISTORY

Since 1986 the government of Victoria has slowly worked towards the closure of institutions for people with an intellectual disability and has progressively moved people into the broader community. Over the past thirteen years the number of people living in State institutions has decreased by two thirds. The Victorian Government had a declared commitment to progressive institutional closure:

> *The deinstitutionalisation of long term residents of public institutions has, since 1970 at least, rapidly gained momentum. The gulf between theories of care and restrictive – often appalling-conditions had become too obvious. Since the early eighties the focus has shifted*

*toward enhancing non-institutional community-based options wherever possible.*

*Large scale, congregate, whole-of-life care is totally counter productive to all reasonable objectives for disability services. An over reliance on specialised facilities can mean a continuation of the tendency to segregate those with a disability: to regard them virtually as 'alien' compared with 'normal' people rather than as 'normal' in almost every respect.*

(Community Services Victoria – Annual Report 1991/92)

## 2.1 One Institution Closes Another Opens

In 1994, in line with the Victorian government's commitment to de-institutionalisation, the former Victorian Minister for Community Services, Hon. Michael John announced, the redevelopment of two state institutions, Janefield and Kingsbury Training Centres. The government planned to move two hundred and fifty people into community based group homes. One aspect of the proposal was however, in direct contrast to the government's policy of deinstitutionalisation. The redevelopment included the building of a new institution. One hundred people were subsequently moved to this new institution.

The rationale for the construction of this new facility was that the people who were moved into Plenty Residential Services (PRS) required *additional support for their physical needs and in many cases their behavioural needs. (*Hon. Denis Napthine MP former Victorian Minister of Community Services radio interview with Gail Jennings 3LO 17/2/97)

The decision to build a new institution caused anger and concern amongst many disability advocacy agencies. In an era when institutions were closing it was generally presumed that present day governments and communities were fully aware of the dreadful effects of institutionalisation, the inherent discrimination arising from their very existence and the inalienable right for **all** people to live within the community.

## 2.2 A Coalition is Born

The decision to build a new institution outraged Victorian based advocacy agencies. Their response was to come together to form the

Coalition Against Segregated Living (CASL). CASL is a coalition of 9 different Disability Advocacy groups. CASL believes that the decision to build a new institution is *a continuation of the outmoded and harmful societal response to disability, of congregation and segregation* and *is not to be tolerated in a modern society that prides itself on its respect for human rights.* (CASL 1997)

CASL has a strongly held belief in the right for all citizens to live in the community, including those who have been labelled as having *challenging behaviours*. The members felt that they *could no longer merely watch and have decided that strong action is needed.* (CASL 1997)

CASL believes that this group of people has been actively discriminated against. A campaign of action was developed.

## 2.3 A Campaign Unfolds

The members of CASL responded by constructing an active campaign, with the aims of challenging the decision to build a new institution and raising public awareness of the issues surrounding institutionalisation. The campaign is multi faceted and includes a media drive, demonstrations, information kits, a legal challenge, and the development of the *Deinstitutionalisation and the Support Needs of People with an Intellectual Disability Project*.

The legal challenge conducted by CASL led to an official investigation by the Equal Opportunity Commission into the government's decision to transfer some people with intellectual disabilities from Janefield to Plenty Residential Services.

*The Deinstitutionalisation and the Support needs of People with an Intellectual Disability Project* carried out research to identify:

- factors which contribute to the institutionalisation of people with intellectual disabilities because of *challenging behaviours*
- alternative models of support and programs for people with *challenging behaviour* that currently exist both locally and in other countries.

- alternative accommodation support programs that will enable people to return to community based accommodation.

Project Tasks included:

- Commissioning Dr. Kelly Johnson to prepare a paper to provide a literature review of the concepts and practices associated with the attribution of the label 'challenging behaviour' to people with intellectual disability. **This report is available from AMIDA or Action Resource Network.**
- Commissioning Moira Raynor (former Equal Opportunity Commissioner of Victoria) to develop a submission to the Victorian Equal Opportunity Commission's investigation into the transfer of former Janefield residents to Plenty Residential Services
- The development of this report, which presents examples of community based accommodation and support models, which exist both nationally and internationally for people with ongoing needs.

## 3. THE NATURE OF INSTITUTIONS

*" When I first went to Sunbury I thought it was going to be a nice place. I*

*thought I was going to be happy. After a few years at Caloola I realised that*

*I wasn't happy at all. I saw a dreadful and abusive side to the institution that*

*I would never have imagined. I was pushed to the limits and the pain and the*

*agony had only just began."*

(Annison, Cincotta & Pentland 1995, p.46)

All systems are considered benevolent in their day, and the institutional system for people with an intellectual disability was no exception. There are many aspects of institutions that make them negative living environments. They are most often geographically

isolated, they segregate people, and are organised around administrative & bureaucratic schedules and routines rather than around personal needs. They have a culture of low expectations of staff and residents and deskill both. Institutions deprive people of their independence and take total control of people's lives.

In 1997 Roger West the Commissioner for Community Services in New South Wales prepared an audit into the performance of institutions *"Large Residential Centres for People with a Disability in New South Wales".*

The report states that *"even when policies have been developed to guide practices, the nature of institutionalisation, inadequate monitoring of practices and lack of compliance results in the centre's failure to protect people living there. 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 Commonwealth Disability Services Act 1986".* (West 1997 p29)

The report also states that *the institutional environment renders some standards and policies impossible to achieve, eg. privacy, flexibility, socialisation, sexuality, dignity and choice. A person's ability to reach individual potential is stifled from the outset.* (West 1997 p29)

During the 1980s the movement towards community care gained momentum. For people born today with an intellectual disability institutionalisation is rarely, if ever, an option. Of the 40,000 people with an intellectual disability in Victoria, only 1,000 remain in institutional care. This is a legacy of the times not an indication of needs. People currently residing in institutions were simply born at the wrong time!

### 3.1 Institution Redevelopment & Cluster Housing

The closure of institutions has ushered in community living options for many people. However it has also resulted in the redevelopment of some institutions into congregate care facilities and cluster style housing. As governments begin closing institutions people with severe disabilities or those labelled as having challenging behaviours are often denied access to community living. They are moved to new purpose built congregate care facilities or other institutions. This phenomenon is known as *transinstitutionalisation.* (Emerson 1994 p120)

This report contends that behind decisions to build new facilities or to redevelop institutions are reasons both complex and hidden. However, by maintaining that these facilities are developed to provide specialised services to people with ongoing needs a clear message is being sent to the community. The implication is that this group of people needs to be kept in housing which separates them from the rest of the community. This messages supports and maintains negative perceptions and community fears. This report contends that people are moved into new facilities as a result of a broad range of circumstances, which may have little to do with individual needs.

Reasons for building new facilities may be:

- Political – including responding to parent lobby groups, union or community pressure
- Economic – ability to save money and resources through sharing
- Administrative – easier to maintain past institutional and administration practices which are already in place.

Cluster housing and congregate care facilities carry over many institutional attributes such as:

- routines designed to serve staff rosters
- administrative needs receiving priority over individual needs
- physical segregation from the community and congregation of people with a disability
- little or no chance to move on to alternative accommodation
- lack of flexibility and/or inability to respond to individual needs or lifestyle choices
- ongoing admissions occur in order to fill vacancies
- isolation from the wider community
- access to community facilities and activities is *dependent on the organisational ability and motivation of staff* ( STAR 1995 p6)
- limited or non-existent accommodation options within the facility

If cluster housing estates are developed governments in years to come may find the need to commit large sums of money and resources to dismantle an outdated system, as is occurring currently with the institution model.

## 4. DEFINING CHALLENGING BEHAVIOUR

Different groups may use the term *challenging behaviour* in quite different ways. Bureaucrats, psychologists, advocates, parents and institutional staff would understand this term differently. It is the term

most commonly used to justify a decision to deny people the opportunity of community living. Using the term *challenging behaviour* to exclude people from community living must be viewed with a high degree of cynicism in light of the following:

- The term is not clearly defined
- The term is highly subjective
- The term is not useful in determining what support a person needs
- The majority of people labelled as having challenging behaviour are already living in the community (Anderson 1999) therefore it's use as a criterion for denying community living is meaningless
- Such a label is a label for life
- The term labels the person without looking for causative factors in the environment

There has been much written about the causes of challenging behaviours. It is recognised that any prolonged confinement in institutions such as prisons, hospitals, prisoner of war camps etc gives rise to institutionalised behaviours. When such behaviour is displayed by people with an intellectual disability who have lived in institutions it is usually labelled as challenging and attributed to their disability.

> *The people in the ward were difficult to live with. They were all too violent*
>
> *and just not friendly. It must have rubbed off on me. If everybody had left*
>
> *me alone I don't think I would have become aggressive. There's only so*
>
> *much abuse you can take without wanting to fight back. If it wasn't the*
>
> *staff that was doing the belting it was another resident.*
>
> (Annison, Cincotta & Pentland 1995, p.49)

In her paper *Challenging People* (1998, p.2), Dr. Kelley Johnson states that the term challenging behaviour *is one that is used frequently and almost exclusively in the literature about people with intellectual disabilities in Britain and Australia and less commonly in the United*

*States. It has emerged from attempts to find a non-prerogative term for problem behaviour.*

However the term has come to be seen as a negative one *leading to the attribution of additional negative characteristics to all people who are labelled as having " challenging behaviour". (Johnson 1998 p4)*

Rather than maintain this negative terminology this report will henceforth use the term, " people with ongoing needs". We believe this reflects the reality of people's need for support without negatively labelling them or their behaviour.

## 5. COMMUNITY LIVING IN ACTION

The following section of the report describes organisations successfully providing community based services for people who have been identified as having ongoing needs. The types of services provided by these organisations range from traditional forms of service delivery eg. group homes, to supported living services providing individualised accommodation options including home ownership. The common link between all of the following organisations is that they unequivocally demonstrate that, with the support, planning and commitment it is possible for all people with intellectual disabilities to live in community based accommodation.

### 5.1 Hornsby Challenge (New South Wales)

The following summary was sourced from articles contained in:

*Beyond Group Homes; Conference paper* Trudy van Dam & Fiona Cameron-McGill

*Behaviour Management – Don't Treat Me That Way* Trudy van Dam & Fiona Cameron-McGill

*Developing Relationships – That's What Friends are for!* Trudy van Dam & Fiona Cameron-McGill

#### 5.1.1 Background

Hornsby Challenge is a community based organisation, which was responsible for facilitating the closure of *Mount Own* an institution for

women with an intellectual disability**.** Mount Own was established in 1964 to provide care for 57 women. The women who lived there had a range of support needs varying from very high to quite low. In 1985 Hornsby Challenge began the process of moving the women from the institution into community based accommodation. This process was completed in 1987.

### 5.1.2 Methodology

Initially the women moved into 3 to 4 bed group homes. Hornsby Challenge, which is committed to fostering community connections, sought to avoid the segregation and isolation, which can accompany deinstitutionalisation. They became aware that the group home style of living not only did not suit everybody but also continued institutional practices. It was felt that the provision of only one type of housing model was hardly conducive to fostering a flexible and responsive service, which recognised individual's needs and preferences. Hornsby Challenge contended that the expression of tensions and the problems which can arise as a result of living in a group home may lead to individual being labelled as having a behaviour problem.

Hornsby Challenge now offers a range of supported living options based on the needs and wishes of the individual. Hornsby Challenge accepts that while some people may choose to live in a group home, a range of accommodation options should be offered for *people who want or need other living arrangements.* Hornsby Challenge has developed a broad range of accommodation options required to meet the needs of a diverse group of people.

Accommodation options provided by Hornsby Challenge include:

- groups of three people living together
- sharing with another person without a disability
- sharing with a person with a disability
- living alone
- boarding with a family
- living in a family home
- Hornsby Challenge claim that a series of attitudinal and structural changes are needed to provide an individualised accommodation service including:
- considering what works best for the person
- not being constrained by past or current options available

- adopting flexible service structures and staffing
- flattening management structures so that key decision makers remain close to the individual being supported.
- flexibility in provision of housing
- separating housing and support issues
- flexibility in staff duties
- making efficient and effective use of resources
- focussing on skill development
- use of generic services
- enlisting support from family and friends

Another aspect of Hornsby Challenge's approach was the development of a "social networking" plan. Hornsby Challenge staff believed that the individuals they were supporting were not developing social networks and in danger of becoming isolated. Hornsby Challenge employed staff to act as social networkers their role was to:

- establish the person's interests
- research the interest
- contact a potential group
- visit the group
- go with the person to the group
- facilitate interaction
- withdraw from the group

### 5.1.3 Behaviour Support

To provide support for people who have been labelled as having challenging behaviour Hornsby Challenge has developed a *holistic approach to behaviour management.* The holistic approach incorporates key elements of a number of methodologies including *Gentle Teaching*, Herb Lovett's *Positive Approaches*, the *'whatever it takes'* philosophy and non-aversive behaviour management. The adoption of the holistic service model has led to a sustained decrease in the instances of challenging behaviour, institutional behaviours, in particular, have completely disappeared eg. rocking, walking in circles etc

**A full description of the holistic approach is provided later in this report.** .

### 5.1.4 Conclusion

Hornsby Challenge provides a practical and well thought out model of service delivery.

Both the accommodation and services they offered are designed to meet the unique needs and lifestyle choices of individuals. Hornsby Challenge has successfully provided support for people with ongoing needs to live in the community. The evolution of Hornsby Challenge has been a

gradual one and was achieved without additional funding. The changes were financed through the redistribution of resources, increasing the use of generic services, and expanding support and community networks.

Hornsby Challenge believes that by restraining growth they have been able to maintain a responsive and effective supported living service. They have now decided to focus their attention on disseminating information, providing support and acting as mentors to other service agencies wishing to move towards supported living.

## 5.2 A Future with Rights – The Right Future Project

*Deinstitutionalisation Project in Newfoundland – Canada*

The following summary was sourced from articles contained in the journal:

*Entourage: Special Issue on A future with Rights – The Right Future Deinstitutionalisation Project in Newfoundland* Volume 8, Number 3, Summer 1994

### 5.2.1 Background

In 1977 the Newfoundland government commissioned an assessment of two institutions for people with an intellectual disability, *Exon House* and *Children's Home*. On the basis of the assessment the government declared that *institutions should play no part in the lives of persons with an intellectual disability* and closed the institutions.

However one hundred and eighteen people with an intellectual disability continued to reside in Waterford Hospital a psychiatric institution. When many of the people first moved to Waterford hospital over 25 years ago it was the only institution dealing with behaviour problems.

In 1993 *A Future with Rights – The Right Future Project* was initiated. The project aimed to move people residing in Waterford Hospital into the community.

The implementation of the project saw a unique partnership develop between two levels of government, the government of Canada and the government of Newfoundland and Labrador and two levels of voluntary sector, the Canadian Association for Community Living and the Newfoundland Association for Community Living

### 5.2.2 Methodology

The project was implemented over a four-year period. Each individual had maximum input into the planning process and their needs wishes and desires were central to the planning process.

Newfoundland was committed to providing a range of alternative accommodation, which reflected the project's desire to match accommodation to individual needs.

The range of accommodation included:

- rental housing (individually and shared)
- family living
- individualised living arrangements examples of this include:
    - support worker's apartment attached to a home
    - finding a new family home for one person to facilitate her wish to live with her parents
- housing co-operatives
- four person group homes
- foster care
- The unique methodologies developed by the project also reflect their strong commitment to person centred planning and community inclusion.

The discharge plan developed by the project broke away from the traditional style of institutional closure which typically involved a *multi disciplinary team developing detailed discharge plans relative to ongoing care and treatment, accommodation, employment, income and so on.* (Rowsell 1994 p10) The three principle stages of the plan were:

i. **Pre Planning**

Pre planning took place within the hospital. During the pre planning sessions individual likes and dislikes, abilities, challenges and aspirations were established. The information was recorded using graphics and text. A Personal Summary Profile was developed. The profiles were written in Plain English eg. *I think it is important for people to know that I . . .*

ii. **Community Based Individual Planning**

The next stage involved the development of an individual support team. Information supplied in the Personal Summary Plan was used to decide who should be on the support team. This team could involve a number of combinations of people including the individuals and their families, friends, social workers, support consultant, a Waterford Hospital staff member and representatives from community service agencies.

(Troope, Reardon & Moulton 1994)

It was the responsibility of the team to find housing, employment and educational options which met the requirements of the person supported. They were also responsible for identifying social and leisure needs. The aim is for the teams to continue indefinitely.

Throughout the process the project worked to involve the person's family and friends. It was an aim of the project that each person leaving Waterford Hospital should have a natural network of family and friends in the community.

In addition to the individual support team each person had an *individual and family support consultant* appointed. It was their role to support the individual to become familiar with the community and to help them choose their home, employment or training, community activities of interest etc.

The Newfoundland Association for Community Living was responsible for developing

community linkages, supporting individuals and families, facilitating community development and ensuring that the people moving from Waterford and their families were at the centre of the planning process.

iii. **Community Development Planning**

A unique and crucial feature of the Waterford closure was the establishment of community support teams. The teams were responsible for fulfilling a c*ommunity development function, enhancing a positive value base with existing generic resources and*

*organisations, fostering generic resources and organisations, fostering awareness and welcoming within the community and developing generic community resources where none exists.* (Entourage 1994 p30)

The closure process also included a strong self-advocacy component. People First of Newfoundland were involved in all aspects of the project. Plain English and graphics were used and regular weekly meetings were held throughout the closure process.

### 5.2.3 Behaviour Support

The Right Futures project employed nine behaviour management specialists. Their role was to provide advice to the individual support teams and to help in the development of behaviour strategies to minimise challenging behaviours. At the beginning of the process they were involved with planning for each individual. However this level of commitment reduced over time.

Initially the methodology adopted was a traditional one of controlling behaviour. Gradually a different approach was to emerge, which was more in line with the principles of supported living. The project began to recognise that people's behaviour often related to environmental and lifestyle factors. Rather than provide continuous behaviour management they worked to identify factors and needs which may have contributed to the behaviour and provided support to meet those needs.

### 5.2.4. Conclusion

The Right Future Project demonstrated that the process of deinstitutionalisation required more than the provision of housing. From the outset the project worked to facilitate true community inclusion. The development of community support teams was a crucial part of this process. Too often by focusing on the mechanics of closure organisations fail to recognise the complex issues, which need to be, addressed to avoid moving people to community accommodation which is as segregated and isolated as any institution. The Right Future Project worked hard to ensure community based support networks.

The project successfully supported people with behavioural issues to move into the community. The gradual move away from traditional behaviour therapies to more creative methods and the diminishing role of the behaviour specialists is evidence of this success.

The final word on the process should come from Don Gallant the Director of Developmental and Rehabilitation Services, Department of Social Services (Newfoundland). He states that the lessons they have learnt are as follows:

- *All person regardless of type or extent of disability, can live in the community*
- *Persons do not have to be eased back into the community. The so-called "continuum of residential services" is a myth. People do not need to progress from one environment to another.*
- *The services we develop are often designed to meet the needs of the system and not the individual. Therefore, all planning needs to be individualised.*
- *It is not persons with disabilities who must be made ready for deinstitutionalisation; instead it is the community that must be educated and prepared.*

## 5.3 Deinstitutionalisation in Region VI (New Hampshire-U.S.A.)

The following summary provides an insight into the development of responsive services for people moving out of an institution. This study focuses not upon the closure process but upon the evolutionary change to service provision, which took place in Region VI, New Hampshire.

The following summary was sourced from the article:

*Coming Home: From deinstitutionalisation to Supporting People in Their Own Homes in Region VI, New Hampshire* Pam Walker March 1993

### 5.3.1 Background

During the 1980's the state of New Hampshire worked to close its state institution for people with an intellectual disability in Lacuna. This closure was a result of a 1981 federal court case.

A state plan "Action for Independence" was developed calling for the creation of twelve area service agencies to provide community based services to people with an intellectual disability.

The service agencies are responsible for case management, family support services and respite. Region VI is the second largest of the twelve area agencies. Private vendors are contracted to provide residential services. Pam Walker describes the development of residential supports within Region VI covering two phases' (1) deinstitutionalisation and (2) development of individual supports and quality of life. During the deinstitutionalisation phase sixty-eight people moved from Laconia into Region VI.

### 5.3.2 Methodology

Each resident moving out of the state institution was assigned a case manager. The roles of the case manager were to monitor service provision, visit people on a monthly basis and develop Individualised Service Plans. Initially people moved into three to four bedroom group homes.

It became apparent that people were unhappy with the group homes. Staff eventually regretted the adoption of this model and felt *perhaps if they had really listened to people at that time, they would not have created these smaller, congregate settings.* (Walker 1993) Staff began to develop an awareness of the growing movement towards person centred service provision. As a result the focus of the agency shifted to provide more individualised support. A range of accommodation options has been developed to facilitate this change of philosophy. The majority of people now receive services in their own home or apartment, which they own or rent.

Examples of support options included:

- providing a man whom exhibited highly abusive behaviour with a home of his own and two full time staff.
- enabling two brothers with severe and multiple disabilities to share a condominium with live in and drop in staff support.

The region adopted a quality assurance process based on John O'Brien's "five-accomplishments" (1) community presence; (2) protection of rights and promotion of personal interests; (3) competence development; (4) status improvement; and (5) community participation. (Walker 1993)

Other quality assurance processes include:

- provision of extensive staff training
- case managers visiting people at least once a month
- monthly progress reports required from service providers
- extensive bi-annual evaluation of every residential setting
- area agency management teams visiting service providers on a monthly basis.
- quality assurance coordinator visiting the service providers quarterly

### 5.3.3 Behavioural Support

The service agency's philosophy has evolved to be similar to that of the Newfoundland's project. Behavioural support is developed to suit the individual and focuses on what the individual is trying to communicate through the behaviour. In all cases the emphasis is on increasing a person's communication opportunities and choices.

### 5.3.4 Conclusion

The experiences of the RegionVI service agencies highlights the importance of avoiding wholehearted commitment to one particular model of service delivery. Adaptations to service systems are necessary to meet individual ongoing needs. The allocation of vast sums of money to large congregate care facilities such as cluster-housing precludes any such changes.

Pam Walker believes that the experiences of region VI can serve as a lesson to other organisations planning institutional closures. She states that Region VI demonstrated the:

- willingness to change things that seemed good in the past but today seemed either not good or mediocre at best.
- ability to recognise when one is providing individualised supports and when and where and why one is making certain trade-offs or compromises: and when one makes trade offs consciously trying to avoid the establishment of structures that will be inflexible and/or difficult to change in the future (eg. purpose built facilities, agency ownership of property).

## 5.4 NIMROD and Andover Developments

*Wales and Winchester – U.K.*

The following two community housing developments are included in this report because the majority of people who access their services have been characterised as having severe challenging behaviours and have lived in the community for ten years.

The following summary was sourced from the article *Ordinary housing for people with severe learning disabilities and challenging behaviours* (David Felce, Kathy Lowe and Siobhan de Paiva 1994) contained in the book:

Severe Learning disabilities and challenging behaviours: Designing high quality services (Emerson.E, P.McGill and Jim Mansell 1994)

### 5.4.1 Background

**NIMROD**

The NIMROD project was initiated in 1981 to provide community based services to people with learning disabilities living in Wales. Sixty four percent of the people who moved into NIMROD were said to have severe challenging behaviour.

**ANDOVER**

Andover housing service began in 1983. The aim of the service was to provide housing for people with the most severe learning difficulties. The service did not exclude any one because of challenging behaviour. As with the Nimrod project sixty four percent of the people moving into the houses were said to have challenging behaviour.

### 5.4.2 Methodology

Both services adopted a traditional group housing accommodation model. NIMROD established five houses and three flats. Each house accommodated four to six people. The residents attended day services. The staff roster for the houses provided for at least two or three staff for early mornings, evenings and weekends and one waking cover at night. Service provision included individual planning, access to social workers and psychologists, keyworkers and a volunteer scheme.

Andover established two group homes with staffing arrangements similar to that of NIMROD service provision including individual program planning, individual teaching and resident participation.

Both services placed an emphasis on individualised planning and the need for a structured living environment.

The benefits experienced by the people living in the housing include:

- Greater participation in every day activities
- Better social life
- Increased family contact

### 5.4.3 Conclusion

Both services have been in operation for nearly a decade. With the exception of one person from NIMROD all of the people accommodated

by both services have remained there throughout this period of time. While the instances of behaviour labelled as challenging did not decrease the researchers states:

*"Using a criterion of ability to cope then, the NIMROD and Andover housing developments have demonstrated over a period of nearly a decade that ordinary housing services can cater for the great majority of individuals with severe learning disabilities and challenging behaviours"*

(Felce, Lowe & de Paiva 1994 p112)

## 5.5 Pleasant Creek Closure

*Victoria*

Pleasant Creek is an institution, which has recently completed a closure process. The people who lived in Pleasant Creek included individuals who have been labelled as having challenging behaviours. The closure is significant as it demonstrates that Victoria has systems, which can support people labelled as having challenging behaviours to move into the broader community.

The information for this report was sourced from:

*An interview with Josie Prioletti - Disability Consultant, contracted to conduct client assessments at Pleasant Creek and Colanda.*

*Pleasant Creek Consultancy Project, Findings, Issues and Options, Presentation Notes 23/5/96*

### 5.5.1 Background

Pleasant Creek is an institution for people with an intellectual disability. It was opened approximately 100 years ago catering for one hundred people in twelve units. Two units were for people who had been identified as having challenging behaviour and were receiving extensive Behavioural Intervention Strategy Team (BIST) intervention. In 1995 the State Government commissioned a report to ascertain suitable accommodation and service options for the 100 people living there.

### 5.5.2 Methodology

Independent consultants, French, Prioletti & Associates were employed to conduct an assessment of the people living at Pleasant Creek and *to provide a complete and accurate profile of each client's abilities and needs, current and future* (French & Prioletti 1995 p3)

The assessment process included three parts:

- Part A - an independent assessment of each individual's abilities (not disabilities)
- Part B - a review of all services and programs
- Part C - recommendations regarding future accommodation and development needs– including recommendations for each individual and recommendations for the centre as a whole.

The methods used by the consultancy team included:

- getting to know each individual.
- extended observations (day and night) in a range of environments including day services to ascertain where people were happiest.
- extended interviews with at least five people who know the client best, including families and past carers
- reading and verification of data.
- following up on past and present assessments and specialists services
- writing of Individual Operational Plans

The consultants identified the effects of congregate care on the individuals living in Pleasant Creek. They were as follows:

- Health
  - -routines/regimes and impact on client's health
  - -food supplements
  - -medical care
- Deprivation
  - -limited life experience
  - -distance from community life, impact on clients
  - -safety issues
  - -awareness of concepts of privacy and danger
  - -effects on mobility
- Acquired Behaviours
  - -waiting/boredom and effect on clients
  - -imitation
  - -self stimulatory behaviours

-self injurious behaviours
-side effects of medication

- Limited Choice
  -routines and regimes
  -client groupings
- Increased Survival Skills
  -competition for staff attention, food, clothes etc
  -minimal interaction between clients and clients and staff
- Family Contact
  -limited family contact
  -relationship discontinuity
  -privacy and meeting places

Predominantly, what evolved from the observations was that people were happiest in small group environments, which provided for more personal interaction. The consultants concluded that the quality of life experienced by the people living in Pleasant Creek would be improved through moving to smaller community based accommodation, with appropriate levels of support, increased staff ratios, opportunities for skill development and experiences. With the exception of one resident (involved with complex criminal justice issues) all residents were assessed as being able to move into the community. As a result of the report the Government decided to close Pleasant Creek and relocate people into group homes.

### 5.5.3 Behavioural Support

Once people moved into community based regionally based Behaviour Intervention and Strategy Teams (BIST) provided accommodation behavioural support.

Support provided by BIST includes:

- intensive support intervention
- direct behaviour intervention
- client assessment
- consultation
- education and training

The behavioural strategies developed by the BIST team are based on the principles of Applied Behaviour Analysis. There are three phases of intervention:

- **Assessment** - including collection of baseline data, and historical and environmental information. This information is then analysed
- **Planning** – The plan is divided into **pro-active strategies**, which aim to produce changes over time and **reactive strategies** for when the behaviour is occurring. Pro-active strategies include the development of ecological interventions, positive programming and direct treatment. Reactive strategies include ignoring, redirection, instruction, active listening, interpositioning and physical management.
- **Implementation** – training and supporting program participants and monitoring program implementation.

### 5.5.4 Conclusion

Josie Prioletti has stated that anecdotal feedback from former staff indicates that some challenging behaviour has decreased. The closure of Pleasant Creek demonstrates that Victoria has developed service systems and accommodation models, which are used to successfully accommodate people with challenging behaviour within the community.

Josie Prioletti (AMIDA 1998) further contends that:

*In my work as a co-ordinator for North-East Citizen Advocacy I had a lot to do with the clients at Janefield most of whom had challenging behaviours. After the review of Colanda Centre – Colac and Pleasant Creek Centre- Stawell all clients bar one were assessed by two independent consultants (including myself) as being able to live in the community. In my opinion the severity of challenging behaviours of Pleasant Creek and Colanda clients were equal to if not greater than the clients who were moved from Janefield to Plenty Residential Services.*

## 5.6 Hirondelle Improved Lifestyle Project

*Victoria*

The following summary was sourced from articles contained in the report:

*KRS Hirondelle; Improved Lifestyle Project – A description and Evaluation of the Move of Forty Men from Unit 30/31, Kew Residential Services to Group Houses in the Community* Gary Radler, Dymphna Laurie & Susana Gavidia-Payne 1999

### 5.6.1 Background

Kew Residential Services is Victoria's largest institution for people with an intellectual disability.

In April 1996 a fire occurred in a Kew residential unit in which nine men died. Forty-two men lost their accommodation in the fire. It was decided that the men would be moved into community based housing. The Hirondelle Improved Lifestyle Project was established in order to facilitate and manage the move.

### 5.6.2 Methodology

Between April1996 and April 1998 the forty men were moved into seven community based group homes. Each house was home to approx five men all of whom had their own bedrooms. Men with similar support needs were placed together. Most of the men had ongoing needs including histories of hurting themselves, damaging property or hurting other people. Some had multiple disabilities. The men who had been labelled as having challenging behaviour *ended up living together*. (Radler et al, 1999 p46)

Individual program plans were developed for all of the men. The plans focussed on teaching skills and increasing community integration. In 1999 an independent team of consultants undertook an evaluation of the Hirondelle Project. They identified a number of key elements, which contributed to the success of the project. These included:

i. **Staffing practices and models**

- Adequate staffing levels (2:6)
- The development of sound staffing practices including the provision of support, encouragement and input into decision making
- Implementing a key worker system whereby each individual has a keyworker
- Shifting away from the traditional institutional shift rosters for staff
- Staff training
- Staffing stability

i. **Communication**

- Facilitating meetings between residential staff, day program staff and family members
- Development of reporting procedures
- Monthly house meetings
- Quarterly newsletter

i. **Community involvement**

- Facilitating involvement in the local community
- Development of relationships with neighbours
- Fostering the involvement of the men in community settings and experiences
- Facilitating full-time attendance at community based day programs for all of the men

i. **Family Contact**

- Fostering increased contact with family and friends.
- Involving family members in the development of Individual Program Plans

### 5.6.3 Behaviour Support

As stated previously many of the men had been labelled as having challenging behaviours. As with Pleasant Creek the local Behaviour Intervention Strategy Team provided staff support. Monthly meetings were held between support staff and members of the regional BIST team. As a result of these meetings intervention plans were developed and implemented. An independent evaluation of the Hirondelle project showed that challenging behaviour had decreased, as had the use of psychotropic drugs. The evaluation also found that there ha*d been an overall reduction in both the frequency and seriousness of incidents that were reported after the men moved into the community.* (Radler et al, p28 1999)

### 5.6.4 Conclusion

The Hirondelle Project demonstrates that not only can community living be a realisation for people with ongoing needs but that it leads to a significant increase in their quality of life.

The 1999 evaluation of the project established that the quality of the men's life in the institution was seriously deficient. In particular they identified that in the institution there existed very low or non-existent

levels of community activity. The evaluation established that in a typical month in the institutional unit the majority of the men experienced no community involvement.

The evaluation report states that *on every count the Hirondelle Improved Lifestyle Project has been a success. As an overall group the men who now live in community houses:*

- *are more actively involved in activities in the community and at home*
- *have learned new skills*
- *have more contact from their families*
- *have been accepted by their neighbours, and in some cases neighbours have been actively involved in the life of the men.*
- *are exercising choice to a degree that they never experienced in Unit 30/31*
- *are demonstrating far fewer and less severe behaviour problems and*
- *are taking much less psychotropic medication than they were.*

(Radler et al, p42 1999)

The evaluation report further states that the family members of the men are very satisfied with their relatives' new homes the opportunities that they are now provided with and the way the services relate to them.

### 5.7 A Review of Three Supported Living Agencies Options in Community Living Centennial Development Service Inc Residential Inc

*Colorado Wisconsin Ohio*

The following summary was sourced from the article:

*A Review of Three Supported Living Agencies* – National Resource Center on Supported Living and Choice 1999, The Center on Human Policy, Syracuse University, Syracuse New York
http://soeweb.syr.edu/thechp/clbnewdi.htm

The Centre of Human Policy reviewed the following three accommodation agencies. They all provide services to adults with disabilities including people with severe and multiple impairments and those labelled as having challenging behaviours. All three of the

services are based on the principles of supported living whereby people are assisted to live in their own homes. The agencies provide the necessary support services and staffing.

The Options for Community Living staff were responsible for initiating another program Neighbourhood Connection. This agency provides support for nineteen people with challenging behaviours to live in their own homes. The report states that the agency is committed to supporting people for whom community living is often considered not possible.

The Centre of Human Policy study states that five factors contribute to the success of the three agencies.

- They are small, non hierarchical, non bureaucratic and personal
- Clarity of philosophy and mission shared by staff
- Creativity in developing individualised supports
- Flexibility of supports
- Commitment by the support staff to the individuals and each other

## 5.8 Okalahoma Community Development Plan

*Okalahoma-U.S.A*

The following summary was sourced from the article:

*Okalahoma Community Development Plan: Providing Opportunities to Live a Typical Life in the Community – Executive Summary (1998)* Commission for Human Services and The Developmental Disabilities Services Division, Okalahoma

In 1994 Okalahoma closed the Hissom Memorial Centre. The successful closure of this institution demonstrated that **all** people living in institutions are able to move into community based accommodation when supported by high quality community services.

The Okalahoma Commission on Human Services is now planning to close two further institutions and provide every person with the services and supports necessary to live and work in the community. The following is a brief description of the process, which will be used in the closure of, Northern Resource Centre and the Southern Resource Centre. The plan is based on the principles of person centred planning and supported living.

In 1998 a Community Development Plan was formulated. Key elements of the plan included:

- integration of the principles of self determination and managed care
- individualised services and support
- continuous Quality Improvement
- a new Individualised planning policy based on the principles of person centred planning
- provision of positive behavioural supports and the development of behavioural support plans when needed.
- using natural and formal community supports
- listening to the person with a developmental disability.
- developing a support team comprised of people, who the person knows and trusts
- consumer satisfaction
- focussing on outcomes

Okalahoma is working towards the development of a consumer driven service system for all people with developmental disabilities.

### 5.8.1 Conclusion

The plan described above is only a brief outline of the deinstitutionalisation plan being developed by the Okalahoma Commission on Human Services. However, it provides an example of the range of issues required to be addressed when creating services and accommodation models, which are based on the philosophies of person centred planning.

## 6. ACCOMODATION AND SERVICE DELIVERY MODELS

The previous section of this report identified that some service providers are moving away from traditional styles of community based service provision for people with an intellectual disability who require ongoing support. They are moving from facility-based service provision towards the adoption of person-centred and supported living philosophies. This section of the report will:

- Describe some of the characteristics associated with traditional styles of community based service provision for people with ongoing needs.
- Outline an alternative style of service provision ie supported living and analyse the approach in terms of implications for people with ongoing needs.
- Identify organisational requirements, which need to be considered when supporting people with ongoing needs to live in the community regardless of the service model being used.

## 6.1 Traditional Approach

Currently in Victoria a traditional facility-based model is the common form of service delivery for people with ongoing needs. Government and non-government agencies manage a range of accommodation options, which may include congregate care facilities, group homes and some smaller residences. Programs and support provided by the agencies are typically based around the accommodation options they offer rather than around the individual.

Services and programs provided by facility-based agencies are often based on the principles of least restrictive environment. Agencies carry out an assessment of an individual's needs and abilities and match them to an accommodation option, which best meets these needs. The accommodation options are usually limited to those managed by the agency. People with the most severe disabilities are usually placed in the "most restrictive" accommodation, the theory being that as people acquire skills they will move along a continuum into more independent settings. In reality people with support needs often end up living in one style of accommodation for years, only moving as a result of administrative or behavioural issues.

The Centre on Human Policy (Syracuse University N.Y.) identifies the following problems with the continuum concept:

- People with severe disabilities get relegated to the "most restrictive" end of the

continuum.

- The most restrictive placements, such as institution, are not necessary
- The continuum implies that people need to leave their homes every time they acquire new skills

- The most restrictive placements do not prepare people for the least restrictive placements
- The continuum approach concentrates resources at the most restrictive end instead of towards typical homes
- The continuum concept confuses restrictions of peoples rights with intensity of their support and service needs
- The continuum directs attention to physical settings rather than to the services and supports people need to be integrated.

The facility-based approach usually includes a process whereby the individuals and their families meet with the agency and develop an Individual Program Plan based on individual needs and wishes. However, there is a limit to the options available for a person with a severe disability or labelled as having a challenging behaviour. Accommodations options are usually limited to congregate care settings or group homes.

The administration and staffing practices of traditional service agencies also restrict the options available to people. Because many group homes do not have staff during the day people must attend full-time day programs. This is an example of administration and resource issues impacting on the ability of an agency to offer real choice.

### 6.1.1 Group Homes

When people with ongoing needs move into the community from an institutional setting it is usually to a group living situation. Group homes have enabled many people to move out of institutions (Kinsella 1994). However, many agencies are now coming to realise that, in some ways, they continue to congregate and segregate people with an intellectual disability.

Hornsby Challenge is an example of a service agency, which has moved from a group home accommodation model to one which offers a broad range of accommodation options, based on individual needs and choices. Hornsby Challenge contends that while sharing a house with three or four people may suit some individuals it should be only one of many styles of accommodation and support offered.

Hornsby Challenge (Van Dam & Cameron) identified the following problems with group homes:

- **Incompatibility** – people are expected to live for many years with three or more people with whom they may have nothing in

common. They are expected to cope and behave "appropriately" in this living situation no matter what differences and falling out they may have with other people living there.

- **Sharing** – sharing can be very difficult for any adults living together who have to share facilities in a house.
- **Limitations on expression of individuality –** group homes tend to operate on a structured basis. In a group home people are expected to shop and eat together and very often to recreate together.
- **Needs of the group take priority –** the ability to exercise individual decision making is also severely limited because the needs of the group come first.
- **Fixed and rigid routines –** routines in group homes tend to be very fixed and bureaucratic because they must cater to the needs of the group rather than the individual.

The problems described above can lead to people becoming unhappy with their living environment. Because they have no control of the situation they will look for ways to express their discontent. Such expressions of discontent are usually labelled as behaviour problems (Van Dam, Wunsch & Hugill 1998)

### 6.1.2 Conclusion

It is important to recognise that the group home model has effectively provided accommodation in the community for many people who have been labelled as having challenging behaviour and whom it was previously thought would be institutionalised for life. It is through the group home approach that governments and services agencies have been able to demonstrate to the community and families that people with challenging behaviours can live in the community. But as with all

models of service delivery it is important to recognise the limitations of providing only one style of service delivery. There is a need to work to improve and change the way we deliver services so that true community inclusion can occur for **all** citizens.

> *It's hard to see how arbitrarily assigning people to any living arrangement*
>
> *could ever bring them happiness. Indeed, as we have learned, group homes,*
>
> *merely continue the history of isolation and stigma.*

(Lovett, Herbert p19 1996)

## 6.2 Supported Living –An Alternative

> " *It seems like my son's whole day is filled with people trying to get him to*
>
> *do better at the things he most dislikes to do. He often resists people when*
>
> *they are trying to help him. It seems like people are always telling him*
>
> *what he is doing wrong. He gets discouraged and angry every day. His*
>
> *whole life is just a series of improvements people want him to make. He*
>
> *doesn't have any plans of his own, or anything to work toward on his own.*
>
> *What is it all for?" (*Tanya Whitehead, M.S 1997)

Supported Living is a service model that has developed over the past ten years. The underlying philosophy of the supported living model is the belief that **all** people can be supported to live in the community **regardless** of their level of disability or behavioural considerations. The model aims to support individuals to have control over their lives through living in their own homes and becoming a part of community.

The individual's wants, needs and aspirations form the basis for deciding where someone will live, whom they will live with, and what services they will receive.

The implementation of supported living for all requires organisations to restructure at every level of their operation. This includes expanding the number of people who are involved in supporting a person. Partnerships are developed, at the person's invitation, between the individual, their family and friends and professionals. Advocates of

supported living believe that by providing people with a lifestyle based on wishes, needs and preferences, many of the behaviours associated with the label 'challenging' will be prevented.

John O'Brien (1993, p.1) states that supported living is a simple concept a *person with a disability who requires long, term, publicly funded, organised assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own* (and makes) *the best use of resources that are available to them to live lives that reflect their values, hopes and aspirations.*

Klein (1994) identifies nine principles underpinning supported living:

i. **Individualisation**

Supported living is developed on an individual basis. It involves understanding and responding to how the person wants to live. It does not mean that they have to live alone but if they wish to live with someone else, they choose the person. It means offering each individual the same opportunities and choices that the general community takes for granted rather than congregating and segregating them because of their disability.

ii. **Everybody is ready**

No criteria's or barriers exist for accessing services. There are no prerequisites because supported living is based on providing each person with the housing and services that match their individual needs and wants. If there is something the person cannot do then the service agency gets someone in to do it.

iii. **Future or Person Centred Planning**

A key to the supported living model is the right of each person to have an individualised accommodation and service plan which matches their individual needs, wants and lifestyle. The term *person-centred planning* (O'Brien. & Lovett 1992) (Institute on Community Integration 1998) (Kinsella 1995) (AAMR1999) is often used to describe a range of approaches, which have been developed to assist

in this process. Common features of these approaches include:

- the person is at the centre of the planning process
- the person is present at all meetings.
- the person invites friends, families, allies, and service providers to create a support network to assist them throughout the process.
- positive listening
- an awareness of the person's whole life is developed including their history, talents, likes and dislikes interests, strengths, and lifestyle aspirations for the future.
- recognition of individual capacities
- the planning process is ongoing
- the development of a plan describing the person's ideal living situation and how it will be achieved.
- if a person has communication difficulties an individual plan is still developed using a combination of observation and information gathering to ascertain the person's history, preferences, likes and dislikes.

i. **Using connections**

Supported living makes use of a wide range of community connections. The people who are involved in the individual's support network should be used to provide access to other people who may be able to provide advice or assistance.

ii. **Flexible supports**

Support should be flexible and adjusted to meet an individual's changing preferences. Support should be determined on the individual's needs and not the routines of the support agency.

iii. **Combining natural supports and using technology**

People learn to provide their own support (where possible). Technology is used to assist in this process eg. communication aids, adapted appliances, remote controls, computers, talking books, video, adapted equipment etc.

**Focusing on what people can do**

Focus on abilities. People are provided with the opportunity to learn to do the things they want rather than what a person's service provider thinks they need. Support is provided rather than forcing an individual to learn a skill that does not interest them.

iv. **Using ordinary language**

Plain English rather than professional jargon are used at both an individual and an agency level.

v. **Ownership and control**

The person lives in their own home and not a service agency house. They sign the lease. The possessions and furnishings in the home are theirs. They choose who will be their support person.

### 6.2.1 Key Components of Supported Living

i. **Accommodation**

A key component of supported living is that the house is the person's own. The types of housing provided can include private rental of a house or flat, public housing, membership of a housing co-operative, sub leasing, boarding etc. The service provider needs to ensure that housing is:

- suited to persons needs and wants
- secure and stable
- controlled by the individual
- integrated into the community
- separated from the service provision

The individual may:

- live alone

- share with a person with a disability
- share with a person without a disability
- live in a family
- home-board
- share with a group of three-four others

i. **Development of Social Support Network**

The person's friends, family and allies continue to be involved in the person's life and are able to provide a range of support and resources including:

- networking
- providing information
- support
- links to new friendships

i. **Development of Community Support Network**

The community can provide a range of resources and support, which can be accessed by the individual including:

- recreation and leisure options
- cleaning services
- home care
- meals on wheels
- generic medical and specialist support

i. **Service Agencies Role**

The service agency is responsible for the overall co-ordination and maintenance of the services required by the person to maintain their lifestyle plan. The service agency's responsibilities also include:

1. **Support workers**

The service agency is responsible for the recruitment and management of direct support workers. Agencies need to ensure that individual support workers are:

- chosen by the individual

- skilled at providing personal assistance
- flexible
- working to develop an understanding of the persons lifestyle preferences
- making efficient and effective use of resources
- focusing on skill development as required
- enlisting the support of the person's family and friends
- maintaining an open and supportive environment.
- identifying risk behaviours and developing and implementing strategies for managing risks
- provided with resources and skilled assistance
- prepared to revise and repair service provision as directed by the individuals needs
- accessible
- recognition from management
- provided with ongoing training and information

1. **Management Systems**

Responsive and thoughtful management practices are another key to the success of support living. Van Dam and Cameron-McGill state that it is important that the management structure of the organisation ensures key decision-makers remain close to the individual being supported. Other management requirements include:

- skilled and competent managers
- flexible staffing arrangements
- development of a responsive structure
- maintenance of accessibility for workers and individuals
- working to sustain and contribute to the relationships between support workers and individuals
- maintaining the focus on providing individualised supports and not falling into group provision.(O'Brien 1993)
- ensuring that all the agencies and people involved in the support process maintain a common mission and strategies.
- provision of ongoing worker training and support
- provision of specialised services and advice as required
- maintaining an atmosphere of respect for all people involved in the process.
- encouraging input from the consumers in all aspects of the service

1. **Resource Provision**

   Methods to develop and coordinate responsive resource provision include:

   - development of a community presence and use of community opportunities

     e.g. housing, transport, employment

   - encouragement of community participation
   - use of generic services
   - flexible housing and resources provision
   - promotion of efficient and effective use of resources
   - making the best use of available funds

1. **Quality Assurance**

   To ensure the ongoing quality of the service provided the service agency can:

   - develop a flattened management structure so that key decision makers remain close to the individual being supported.
   - ensure grievance procedures are available
   - ensure individuals know how to raise concerns and make complaints.
   - foster a supportive and open environment
   - encourage the involvement of advocacy and self advocacy agencies
   - promote self advocacy
   - enable people with disabilities to maintain choice and control

### 6.2.2 Organisational Issues

This report has shown that it is possible to provide community based accommodation and support options for people with ongoing needs. However, in order to ensure the ongoing success and quality of service delivery there are fundamental issues( Fyffe1999) (Van Dam, Hugill & Wunsch) which need to be considered when developing any style of support model including:

- development of a collaborative approach

- flexible staff rostering
- availability of a skilled, competent and supportive managers
- provision of practical information and emotional support
- access to specialist advice concerning the analysis of behaviour and development of support options.
- ongoing staff development and training.
- availability of resources
- worker continuity
- development of efficient staff recruitment policies
- management based on good information and commitment to principles
- ability to deploy resources as required
- accountability for ensuring individual needs are met.
- the need for a high level of personal commitment on behalf of staff and management. (One solution to this problem is to ensure that supported living agencies remain small and responsive. Supported living service delivery is not suited to the current evolution of large service delivery organisations)
- the potential for the individual to become isolated and lonely. Agencies must
- work to ensure that community support networks are established and maintained.
- conflicts, which can arise around the interpretation of a person's, needs and wishes, particularly those with limited expressive language.
- the lack of people experienced in the implementation of person-centred planning and supported living.

Problems can arise with any model of service delivery. To ensure quality service provision it is important to identify and plan for problems (O'Brien 1993). These problems are not insurmountable. Supported living agencies actively share their learning and experiences and many of the publications referred to in this report are an excellent starting place.

### 6.2.3 Conclusion

Supported living is an approach, which requires a great deal of commitment, and a major change to the way services and accommodation are traditionally provided. However the development of a service system based on the principles of supported living can provide significant benefits for people with ongoing needs. A range of challenging behaviours may be reduced or prevented by providing people with a lifestyle based on their individual needs and wants.

Supported living enables people with ongoing needs to obtain full community inclusion and citizenship.

## 7. ALTERNATIVE MODELS OF BEHAVIOUR SUPPORT

This section of the report outlines three models of behaviour support developed as an alternative to traditional behaviour therapies. The previous section of this report identified the trend towards the provision of individualised accommodation and service models as an alternative to the more traditional facility based model of service delivery. A similar trend has occurred in the provision of behaviour support for people labelled as having challenging behaviours. The models described below have moved away from the traditional approaches, which concentrates on modifying a person's behaviour. They focus on identifying the person's needs, preferences, concerns and strengths and the importance of responding to these.

The Coalition Against Segregated Living does not endorse or advocate any of these models. There are however aspects of them all which have value as a tool in supporting people with ongoing needs to live in the community.

### 7.1 Positive Approaches

The information contained in this section was sourced from:

*Articles contained in the Pennsylvania Journal on Positive Approaches*

> *It took me a long time to realise that people labelled "retarded" had*
>
> *very different lives because of this label we psychologists had given them.*
>
> *"Those people" who might need help in ways large and small, almost*
>
> *always pay for the help they need with their freedom, their dignity and*

*a general loss of control over their own lives. (Lovett 1996, p.3)*

In his book *Learning to Listen* Herb Lovett questions the use of behavioural therapy techniques from a political and social perspective. He presents a range of arguments against the use of behavioural practices such as reinforcement schedules, labelling, restraint, ignoring and redirection. His book discusses positive ways of providing individuals with support. He believes first and foremost that we must *learn to listen* and *listen to learn.*

He explains that listening involves, listening to what is said and meant, viewing actions as communication and the ability to take people seriously. He advocates the use of positive approaches such as listening, and responding to peoples needs preferences and strengths.

Many of the philosophies espoused by Herb Lovett have being incorporated into a " Positive Approaches" methodology developed by a group of Pennsylvania service providers. (Barol 1996) These providers include agency administrators, residential workers, psychologists etc. This group met to explore how people with challenging behaviours were being supported. From these meetings emerged the Positive Approaches technique. Positive Approaches committees now exist throughout Pennsylvania (Thaler 1997)

### 7.1.1 Key Components of Positive Approaches

i. **Environment**

The original group found that in three-quarters of the situations a person's *behaviours change for the better when they are helped to live in a manner that better meets their needs.* (Barol 1996) They argue that many people who have been labelled as having

challenging behaviour live in group homes or institutions. They claim that the aspects of living in those environments that can create challenging behaviour include:

- mealtimes that don't meet the person's needs
- lack of access to snacks when hungry
- no choice of menu
- lack of exercise
- limited opportunities for fun

- few loving relationships
- lack of hobbies or the opportunity to develop interests
- few reflections of being valued
- isolation from the community
- no way to earn money
- limited transportation and access to friends and activities

It is their experience that the environmental issues listed are usually not investigated. They advocate working to change the person's environment to meet identified needs.

i. **Communication**

Positive Approaches advocates contend that often the person presenting a challenge is unable to communicate needs and wants. They further contend that the behaviour often disappears when a person communicates needs and those needs are accommodated. Barol (1996) recommends that support workers should do whatever is possible to assist the individual to communicate.

Assistance can include:

- providing communication boards
- trying facilitated communication
- using graphics
- consulting with those who know the person to gain understanding of the individual's body language

Bryen & Di Casimirro (1997) state that alternative or additional communication techniques need to be found for people experiencing communication difficulties. They further state that *when a successful technique (or device) is found for the person who has challenging behaviours it is an enormous breakthrough.*

The Positive Approaches Newsletter (Volume 1, Number 1) outlines the following case study as an example of a *breakthrough* which occurred as a result of facilitated communication techniques:

*Jennifer who is a young adult with autism, has been the key person in developing her own behavioural support plan. She has been able to be very specific in describing*

*her internal perceptual circumstances. Some of Jennifer's suggestions to her supporters involved major life changes; others involved seemingly insignificant factors, which were supporting her difficult behaviours. Armed with that information, those working with her have been able to significantly reduce many of her major behavioural problems. Concurrently after only 14 months of facilitated communication training, Jennifer is approaching independence. She is now printing independently, playing board games independently and trying out new activities. She is clearly a bright, energetic young woman who has finally escaped the glass bubble and some of the labels, which had been her life until 14 months ago.* (Lapos 1996)

i. **Assessment**

Positive Approaches advocates believe that even after environmental and communication needs have been addressed, some people will still have problems. Barol claims that *every*

*concern that is relevant to typical citizens is also relevant to people with developmental disabilities including***:**

- pain
- mental illness
- trauma and loss
- sexuality issues
- abuse
- loneliness
- powerlessness
- addiction

She suggests that for many of the problems listed there are a wide range of community based support options which can be accessed.

**iv Hanging in There**

Positive Approaches advocates warn that even with a range of supports in place the problem may continue for a long time. (Barol 1996) They advocate that the person supported needs to:

- develop trust
- learn to adjust to the changes that have been made

- experience the positive regard of others
- be supported by one person who is prepared to provide ongoing support

**v Support Workers**

The support workers role includes:

- having fun and celebrating the person
- being with the person not the problem
- individualising everything
- building good relationships and consistency
- using of technology to improve environments.
- providing the person with control over their lives
- supporting self determination

### 7.1.2 Use of Medication

Positive Approaches advocates (Lee 1996)(Gordon 1996) believe that medication should be used

only for:

- behaviours resulting from or exacerbated by a treatable, biologically based psychiatric disorder
- behaviours resulting from or exacerbated by a treatable general medical disorder
- short term management of behaviours which endanger the health or safety of the individual or other person

Kathy Lee (Co-founder of Supports Inc.) argues against the use of medication and restraint as a *treatment* option. She contends that these techniques are used to help the individual *to be more normal.* She further contends that the techniques used are not "normal'. She states:

*As an equation this would appear something like:*

***weird behaviour + weird treatment = normal person***

Christopher P. Gordon MD (Medical Director of the Pennsylvania Office of Mental Retardation) states that long term use of medications such as Thorazine, Haldol and Navane ***** to control behaviouris not appropriate because:

- long term use can lead to serious side effects including depression, blindness, motor disturbance etc.
- they can mask symptoms eg. sleep disturbances, mood swings

He warns however that discontinuing medication can produce a range of withdrawal symptoms, which should be recognised and planned for. He states that while the process of withdrawal can produce problems *considering the devastating consequences of remaining on anti-psychotic medication however, we really have no choice but to try.* (Gordon 1996)

*****In 1997 –1998 in Victoria 793 people were on chemical restraint (including Thorazine and Haldol), 26 people had mechanical restraint and 22 were secluded for a period of time. (IDRP Annual Report 1997-98)

### 7.1.3 Conclusion

In summing up the philosophy of Positive Approaches Kathy Lee (1996) states:

*It is an ongoing process of learning about the best in people and supporting them through the worst. I know that it is a "we" thing and not a "me" thing. I know that it is not a technique or method but more a way of thinking and acting - about trying and trying and trying again and not accepting the unacceptable. I know that Positive Approaches is based on a system of values that begins with the fact that everyone's life has meaning and purpose. I know that whatever we are doing in the name of helping people, it has to be real and respectful. I know that it has something to do with putting myself in a person's shoes and asking " Would I want people to be doing this to me?*

## 7.2 Gentle Teaching

The information contained in this report was sourced from:

*Foundation for Gentle Teaching in the Netherlands Internet Site*

http://utopia.knoware.nl/users/gentle

*Gentle Teaching International Internet Site*

Http://www.gentleteaching.com/Articles/vol2no2.htm

Gentle Teaching is a technique developed by John J McGee Ph.D. The technique is based on the principles of non-violence and has been used for supporting people with challenging behaviour.

Gentle Teaching focuses on four primary goals of support:

- teaching the person to feel safe with support staff
- teaching the person to feel engaged with support staff
- teaching the person to feel unconditionally valued by support staff
- teaching the person to return unconditional valuing to support staff

Another aspect of Gentle Teaching is the incorporation of the Psychology of Interdependence, which focuses on a human being's need to be connected and have companionship. Gentle Teaching advocates contend bonded relations are fundamental for developing basic human values into a moral life and into personal goals. Gentle Teaching purports that if people don't feel safe with others they will not learn from them and that the basis of learning is trust and safety with others and comes from a emotional stability within (McGee 1990).

Gentle Teaching comes from eight basic values (McGee 1990) that relate to an individual's quality of life. The values are:

- bodily integrity eg. health, food, clothing etc
- feeling safe
- feeling self-worth eg. seeing oneself as good, being recognised as a person.
- having a life structure eg. having a life plan, having a daily routine
- a sense of belongingness eg. having a home ,feeling companionship, having friends
- social participation
- having meaningful daily activities
- inner contentment

Gentle Teaching recognises that each individual will have different priorities and place varying levels of importance on each of the life values.

Gentle Teaching suggests that people with challenging behaviour may use the behaviours as a way of expressing his or her own values eg. *In order to feel safe you may be aggressive to someone else or in order*

*to create structure, you act aggressively thereby provoke a predictable reaction of your care-givers* (Foundation for Gentle Teaching in the Netherlands 1999).

Gentle Teaching believes that in working to support a person one should determine each of the basic values that are important to each person, determine what expressions the person is using to achieve those values and teach alternative means of expressions.

If a person is lacking one of their essential values then work should be undertaken to remedy the situation. eg. *A person needs to feel safe. If a person lacks this essential value, the caregiver has*

*to define this as a primary goal and effectuate a plan of support around this* (Foundation for Gentle teaching in the Netherlands1999)

John McGee states that governments and agencies should not:

- congregate large numbers of people together so that warm relationships are hard to establish.
- look for ways to control instead of to nurture
- use behaviour modification analysis and planning as the be-all-and-end-all of what we

must do

- train care-givers in the use of physical management, chemical restraint and punishment-based intervention
- write policies that encourage congregation, segregation and control rather than interdependence, companionship and community.

## 7.3 Holistic Approach

In section two of this report we provided a summary of the holistic approach to behavioural support developed by the Hornsby Challenge Ltd. The following is a more complete description of the approach reprinted with permission from the booklet "Behaviour Management – Don’t Treat Me That Way" Van Dam and Cameron-McGill 1997:

A holistic approach to behaviour management:

- focuses on preventing behaviour from occurring rather than waiting for the person to reach a crisis point.

- relies on understanding the person with the disability very well
- is based on the assumption that those closest to the person play a crucial role in understanding the person and his/her behaviours
- places greatest importance on investigating all possible factors that may contribute to a persons behaviour

If we accept the contention that behaviour has a function, is purposive and inherently meaningful, then surely the onus is on us to elicit and discover that meaning. There is only one rule in effective behaviour management and that is – if I want this person's behaviour to change then the first thing that must change is me, my approach and my thinking about the person. It is no longer sufficient to simply manipulate antecedents and consequences.

**Preventing Challenging Behaviours**

All to frequently, challenging behaviour is caused because we do not take the time to listen

(either verbally, through alternative communication or behaviour) to what the person with a disability is saying. When we do listen we frequently disregard what they want until they are forced to use more and more desperate expressions of their distress. Finally we find ourselves faced with severe challenging behaviours and usually then resort to punishing the person for their behaviour.

If we provide the individual with the lifestyle they desire and need we will avoid most challenging behaviours.

In order to do this we must consider how we can: -

- better relate to and understand this person
- change the way we interact with this person
- alter the environment to make it easier for the person to participate in it
- provide this person with a stimulating lifestyle that won't necessitate expression through inappropriate behaviours

We must apply our insight as thoughtful and involved human beings to the task of understanding the person.

This more holistic approach to behaviour leads us to consider the " big picture"

- What would a really satisfying lifestyle look like for this person?
- What type of living situation house/housing would really suit who they are?
- What sort of ways of spending leisure time would really reflect this person's personality and express their gifts and interests?
- What sort of friends and acquaintances would they enjoy spending time with?

Some practical issues to address which help prevent behaviour management issues include:

i. **Establishing a respectful, trusting relationship**

If we respect people with disabilities and listen seriously to their concerns (whether expressed verbally or through alternative communication such as signs or actions) they in turn will be more likely to communicate their concerns to us in an appropriate manner. We will need to consider things like:

- changes to the physical and/or social environment
- pairing liked and unliked activities to make it more motivating to get through the unliked activities
- the persons comfort
- ensuring that the person has sufficient entertainment and activity
- ensuring the person has valued, individual attention
- asking the person how they are and what they want
- stress reduction techniques

i. **Identifying valued, positive behaviours**

Very often we ignore the positive constructive attempts people with disabilities make in their lives and focus persistently on their deficits, mistakes or inappropriate behaviours.

ii. **Ensuring that positive behaviour is reinforced**

Having identified positive behaviours, we need to ensure that those behaviours are reinforced.

## Exploring the causes of behaviour

A more holistic approach to behaviour difficulties needs to incorporate all aspects of the person and their circumstances – hence the growing movement to use comprehensive environmental analysis. Many features may affect a person's behaviour and all need to be explored:

- emotional or psychological issues
- medical issues
- physical limitations
- social and physical environment
- personal history

## The Purpose of Behaviour

All progressive practitioners focus on a conception of behaviour as purposive and an onus on the observer to elicit the underlying causes of the behaviour as a crucial step in addressing the behaviour. Meyer and Evans (1985:55) description of three main types of causes is particularly useful:

i. **Social/Communicative**

The term social/communicative is not be confused with the popular term "attention seeking behaviour". When we say, "attention seeking" we usually mean that this person is "attention greedy" ie. they want too much attention and we're not going to give them any more than their quota. Rather, the term social or communicative refers to the behaviour being an attempt by the person to communicate or to engage socially. (A very normal response)

ii. **Self Regulatory**

Self-regulatory refers to an understanding of the behaviour as the person's attempt to regulate their arousal level. The person may have difficulty adjusting to the demands or lack thereof of the environment.

iii. **Self Stimulatory Behaviour**

The traditional response to self stimulatory behaviour is to focus on eliminating the behaviour by weakening or eliminating the automatic reinforcement that it gives (eg. wearing gloves so that repetitive hand rubbing to clapping is not so stimulating). This can be turned on its head by attending to the desire of the person for a stimulus ie. by enriching the person's environment with a variety of engaging, non-contingent stimuli (Mac & Roberts, 1993:126).

**Giving the person what they want**

From understanding the meaning behind the behaviour and from understanding the behaviour as functional to the person we can ask ourselves: "now that we know what the person wants can we give it to them?"

Nine times out of ten the answer will be yes. Contrary to our normal socially sanctioned response. (i.e. you behave badly, I won't let you get away with it because you have to learn to behave properly) we propose that a more successful approach is to say:

" We know what you want, yes you can have it and we'll make sure you get more of what you want so that you will know that you don't have to go to desperate measures to get what you want."

Maybe a person's behaviour says "I'm angry because I don't have any control over my life – I'll hit you" In this case our response would be to " Give the person greater control over their life"

If the person says "I don't like doing housework, I want to interact more socially, with lots of people" We say " get a cleaner and get out of the house more!" "Now I'll teach you how to ask for it without having to hit me."

## 8. CONCLUSION

Many people, who live in institutions today, have done so since they were young children. During these years they have been segregated from the general community and denied many of the basic human rights we all take for granted. Their institutionalisation has been a life sentence merely because they were born in an era where institutionalisation was a blanket response for people with an

intellectual disability. Today, while there is some institutionalisation, it is a common experience of people born with an intellectual disability to remain in the community. As a community we have a moral obligation to do **whatever it takes** to ensure that all people with an intellectual disability have the opportunity to become part of the broader community.

The research contained in this report demonstrates conclusively that community living is achievable for all people regardless of their level of disability. This report does not claim to present a definitive accommodation and support model for people with ongoing needs. It does however identify deficits, which occur with a traditional facility based method of service delivery. It offers alternatives based on the principles of supported living. It is clear that many of the organisations outlined in this report have developed support models which are designed to meet the particular needs of the individuals they serve. While each model is unique, common elements include:

- provision of accommodation based on the principles of supported living
- service provision based on person centred planning
- pro-active approaches to ensure community inclusion
- use of a positive approaches models of behaviour support

The following quote was provided by Nancy Weiss, the President of the internationally recognised British organisation TASH (an advocacy organisation for people with severe disabilities), who responded to a request by the authors of this report for a statement on the redevelopment of institutions:

**TASH strongly believes that all individuals with disabilities can be served in their home communities with the range of supports needed by each individual for success. We oppose new construction and major renovation of institutional settings as continuing a legacy of discrimination and segregation. All citizens with disabilities have the right to live in their communities with support for full participation in work and leisure.**

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**Useful Websites**

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National Program on Self Determination http://www.self-determination.org
American Association on Mental Retardation http://www.aamr.org
TASH http://www.tash.org
Institute for Community Inclusion http://www.childrenshospital.org/ici/
Ontario Association for Community Living http://www.acl.on.ca
National Home of Your Own Alliance http://alliance.unh.edu/
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http://www.libertynet.org/speaking/index.html
Canadian Association for Community Living http://www.cacl.ca/
The Institute Roeher http://indie.ca/roeher
Publications by John O'Brien and Connie Lyle
http://soeweb.syr.edu/thechp/rsapub.htm
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http://www.napanet.net/business/personal/ASA/ASA.html
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Supported Life Institute http://www.supportedlife.org/
Coalition Against Segregated Living Information Kit
www.infoxchange.net.au/AMIDA

# TEACHING NOTES

The following teaching notes serve as an outline for the development of discussions and activities based on issues raised in the *Challenging Institutions* report. The notes include ideas, quotes, and case studies, which can be used to generate group discussions. Each topic also has information sheets, which can either be photocopied onto overhead projector sheets or photocopied and handed out.

These notes provide a starting point for exploring issues raised in the *Challenging Institutions* report. Other sections of the report may be reproduced or reprinted in order to facilitate further activities and/or discussions of ideas and issues not covered by these teaching notes.

## *Topic One*
## *Politics of Labelling*

### Aim

- To introduce the concept of labelling and the impact it has on people with an intellectual disability.

### Background

For people with an intellectual disability the label of challenging behaviour has lifetime implications. The *Challenging Institutions* report describes how the label is often used to justify a lifetime of institutionalisation and the implementation of a range of behavioural therapies designed to change the person.

### Materials

Overhead One

Overhead Two

Overhead Three

### Method

1. Display Overhead One - use the overhead to generate a group discussion on possible action plans, which could be developed for Maureen. Once this activity is completed, proceed to the second overhead.

2. Display Overhead Two - use the points made to generate discussion. Refer back to the ideas discussed by the group after viewing the first overhead.
3. Display Overhead Three – use the quotes and questions to generate discussions and identify problems associated with defining the term challenging behaviour.

**Suggested Reading**

**Learning to listen: positive approaches and people with difficult behaviour** *Herb Lovett* (Paul H.Brookes Publishing Co. Baltimore, Maryland 1996)

**Pennsylvania Journal on Positive Approaches**
**http://www.quuxuum.org/~greg/journal**

**Related Topics in Report**

The following sections of the report could be photocopied and used as further hand outs

**The Nature of Institutions** (pg 4)

**Institution Redevelopment & Cluster Housing** (pg 4-5)

## *Topic Two*
## *Supported Living*

**Aims**

- To introduce the concept of Supported Living as an alternative to current housing models such as the group home model.
- To identify the importance of person centred planning in the development of a supported living accommodation model.

**Background**

Supported Living is a service model that has developed over the past ten years, particularly in the United States. The underlying philosophy of the supported living model is the belief that **all** people can be supported to live in the community **regardless** of their level of disability or behavioural considerations. The model aims to support

individuals to have control over their lives through living in their own homes and becoming a part of community. People labelled as having challenging behaviour are often perceived as needing the more restrictive styles of accommodation including institutions, cluster housing, or group homes. The supported living model challenges this perception.

**Materials**

Handout One

Handout Two

Handout Three

**Method**

**1.** Give out **Handouts 1,2&3**

Use these handouts to generate discussion. Discussion points may include:

- Identifying the differences between the supported living model and the group home or continuum model of service delivery.
- The strengths and weaknesses of each model of service delivery.
- Identifying the differences between the principles of person centred planning and the current methods of Individual Program Planning (Victoria).

**2.** Give out **Handouts 4 & 5**

These handouts detail a supported accommodation model developed by Hornsby Challenge. The model is based on the principles of person centred planning. Hornsby Challenge progressed from a group home model of service delivery to that of supported living. The implementation of a support service delivery model was achieved without any additional funding.

Use the handout to generate discussion. Discussion points may include:

- The benefits and/or problems associated with the provision of accommodation and services based on the principles of supported living.

- How a traditional method of service delivery could be redeveloped to enable an organisation to provide accommodation and services truly based on an individual's needs and desires.

**Suggested Reading**

Beyond Group Homes *Trudy Van Dam & Fiona Cameron –McGill*
Ph:(02)9874-8544

Centre on Human Policy Website
http://soeweb.syr.edu/thechp/clbnewdi.htm

**Related Topics in Report**

The following sections of the report could be photocopied and used as hand outs:

**Deinstitutionalisation in Newfoundland** (pg 9)

**Deinstitutionalisation in New Hampshire** (pg12)

**A Review of Three Supported Living Agencies** (pg 20)