

## **A Position Paper**

Setting A Positive Agenda
For People With Disability
With High Or Complex Support Needs
Living In Roarding Houses And Hostels

# **Queensland Advocacy Incorporated**



May 2001

OPENING DOORS TO LIFE

Setting A Positive Agenda With People With Disability
With High Or Complex Support Needs Living In Boarding Houses And Hostels

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RECOMMENDATIONS FOR STATE GOVERNMENT

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#### 1. INTRODUCTION

#### This position paper is not about the future of boarding houses or hostels.

We believe that boarding houses and hostels have a role to play as housing options for people who seek to have budget accommodation, sometimes with the possibility of a few additional daily life services. In this context, what happens with regulations and standards for boarding houses and hostels is a matter between the industry and government to decide, in the context of what is good and safe housing for all.

#### This position paper is about people with disability and their futures.

Some people with disability with high or complex support needs are living in boarding houses and hostels throughout Queensland. Because of their personal life journey, they have ended up in congregated housing with minimal support and have become very vulnerable to isolation, neglect, abuse and living wasted lives. Such living and lifestyle support arrangements are quite inappropriate and at times quite dangerous.

We believe that this identifiable group of people with disability have become a distinct grouping because of a long legacy of government indifference to their plight, tied to the expedience of having a roof over their head. Even if the industry is cleaned up, we believe that people with disability with high or complex support needs, require much more than a room governed by building regulations, accommodation standards and maybe a bit of support with meals or a few extras on the side.

In the wider sector, much has been done for others with disability who have lived in similar settings. By the very nature of their size and closed culture, large, congregated living institutions are now seen as unsuitable places to live or to have adequate supports to enable a decent life. Yet people with disability living in boarding houses and hostels have had no similar consideration of their lives.

We urge that any attention now being focussed on people with disability who have high or complex support needs who live in boarding houses and hostels, be set in the context of what is seen to be a decent life for any citizen and be governed by similar principles as those embedded in the Disability Services Act and the Strategic Plan of Disability Services Queensland.

Positive change would not mean just tinkering around the edges to provide a little group or individualised support in amongst their current congregated housing. Consideration must be given to options that are based on knowing the people involved and planning with each individual about what a decent and desirable future might be and how it could best be attained. On the basis of such personalised knowledge, the doors can be opened to the possibilities of building new lives; lives that are not isolated, nor where people are open to a culture of neglect or abuse.

This position paper puts forward positive suggestions for short and long term strategies about how people with disability with high or complex support needs who live in boarding houses and hostels, might be identified and supported to begin the journey of exploring and gaining proper supports which

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enable them to reconnect with ordinary life.



#### 2. WHO THE PEOPLE WITH DISABILITY ARE

In this paper the term "people with disability with high or complex support needs" has been used to identify people who have an ongoing need for others in their lives to provide extra, intentional support above the need of a few extras as part of an accommodation arrangement.

Their residency in hostels and boarding houses has often resulted when no appropriate accommodation has been available and they have simply needed a place to stay, often at short notice. Over time a boarding house or hostel has become their home, and in most instances they have had no other choice but to remain there, that is, if they have been seen to fit in. If not, they may have moved from one to another, with no security of tenure. Such arrangements have been made with full cognisance of government, whose staff have often been their placement officers.

These people with disability have come from a variety of backgrounds and lifestyles, but a common thread is that most have been negatively labelled and pushed to the margins of societal and community life.

Men and women of a range of ages:

- Living in segregated facilities
- · Living in mixed facilities

#### People with:

- Intellectual disability
- Sensory disability
- Episodic psychiatric disability
- Long term psychiatric disability
- Limited physical mobility
- Wheelchair mobility
- Challenging behaviour
- Multiple disability
- Drug and alcohol problems

People from criminal justice system

- In trouble when they have not coped with the demands of living in the community
- From prison

People evicted from services

- From other housing
- From disability services where they have challenged the service system

People from institutions with no place to go and no supports:

- Psychiatric hospitals
- Long stay psychiatric institutions
- Centres for people with intellectual disability

People with disability with different life circumstances:

- In poverty
- With not much disposable income
- In protection schemes such as Public Trust, Adult Guardian
- Isolated with no family or significant connections to others
- Having lost valued roles in:
  - o Family
  - o Job
  - o Home
  - o Social networks
- From damaged relationships
- From abused lives
- On medication
- With no other housing options
- With no support
- Alone following death of parents
- · Of different ages including elderly



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#### 3. WHY THE PEOPLE WITH DISABILITY ARE VULNERABLE

Over the years many inappropriate practices have happened which affect the lives of people with disability with high or complex support needs living in boarding houses and hostels. The following stories have been told to QAI from a range of sources including the people themselves. They are all indicative of inappropriate placement by professionals and inappropriate support practices.

#### About tenancy:

- has no tenancy rights, tenure, etc
- is constantly moved and is placed in a number of different hostels, eg moved 28 times in 7 years
- chooses to sleep on the street rather than return to a hostel following an incident there
- runs away continually because of fear of living there
- spends significant time at shopping centres or on the street to avoid being at home there
- · is thrown out or told to leave
- is continually readmitted into hospitals
- is a captive in the hostel system due to lack of support to live elsewhere

## About relationships:

- lives a long distance from family or friends
- has limited or no relationships outside of co-residents and managers
- is isolated within the living environment with no relationships of substance with any one living there
- cannot have outsiders involved in their life as the place is closed to others
- finds everything is dealt with in house and is a closed shop
- is answerable to the landlord/manager
- has hostel doctor, not own GP
- is grilled every time they go out, have a visitor, spend money etc

#### About control:

- makes a complaint, finds others in collusion against them and gets retribution
- makes a complaint and is moved or medicated
- is given a variety of medication to control their behaviour
- has constant feelings of unresolved anger and disempowerment

## About abuse:

- is mixed inappropriately with others who take advantage of the person, physically, sexually, financially
- has no lockable places and has possessions stolen regularly
- is involved in violent or submissive relationships with other residents
- is abused by others who live or work there
- is, as the victim of abuse, moved elsewhere
- becomes involved in or is the perpetrator of abuse
- has regular police intervention to settle disputes among residents

#### About daily life:

- is treated with lack of respect, lack of trust, lack of choice, lack of privacy, lack of independence
- has everyday personal care needs met by other residents
- has a bed and room that is not cleaned daily when it is soiled or dirty
- is constantly unkempt and looks unwell and uncared for
- has no consideration of personal and other fundamental needs being met
- has no thought or action about best interest in relation to their vulnerability
- is expected to do the work of the hostel, eg peeling vegetables all day
- is idle all day, just sits around living a wasted life

#### About money:

- has minimal if any disposable income after paying rent
- cannot afford to move around their community, making them captive of their living situation
- has money managed but no monitoring of how that is done



#### 4. HISTORICAL BACKGROUND

Hostels and boarding houses have had a long history of being affordable housing. Whereas in the past they were seen to be a part of mainstream housing initiatives, over recent decades they have catered more for those living marginalised lives. This change has come about for a number of reasons, one being people having nowhere to go when family members could no longer cope, or died without having other support alternatives in place, another being the policy of deinstitutionalisation.

When people began to leave institutional centres, hospitals and nursing homes with the intent that they returned to community living, little thought was given to the supports that might be needed. Many people had lost contact with their families and friends and often were discharged many kilometres from the communities where they had grown up, lived or worked. When wholesale discharging began, communities had little capacity to support people with health, housing or other service infrastructure to enable them to reconnect again with ordinary life. Also as Queensland has had a poor record of community based mental health and preventative support strategies, people with disability continued to go into institutions only to come out with nowhere to go or were left with families with no supports.

The number of boarding houses and hostels in both city and rural areas grew during this time, with many being established by doctors, psychiatric nurses, other ex staff of institutions as well as farmers wanting to diversify their income base by taking in people who would live and work on their properties. For many, these housing alternatives were seen to be better than remaining incarcerated in traditional institutions. At the same time they became available as alternatives when families were no longer able to be the prime means of support to the person.

However for over three decades, concern has been raised about the quality of life of people who require more than just what property owners and business operators of boarding houses and hostels could provide. In addition there have been major concerns about the primary responsibilities of these owners and operators for the maintenance of the physical condition of buildings, the upkeep of their contents, hotel style services and proper operation of the accommodation facility.

Since 1977, we have been aware of at least eleven important attempts to address the issues of poor quality housing and poor quality support of the people who live in boarding houses and hostels. These have included government working party groups, reports, internal investigation units, ministerial taskforces, law reform projects, boarding house support projects, discussion papers, the Burdekin Report and the establishment of the Hostel Industry Development Unit (HIDU) to highlight a few. The majority of these investigations have recommended regulation of the hostel industry, which still has not eventuated. Meanwhile people with disability, who become extremely vulnerable when placed in unsupportive and unsafe housing, continue to be accommodated in boarding houses and hostels.

However, although regulation is extremely important to help to ensure safe and decent housing for all, we believe that regulation in isolation is not enough. It must go hand in hand with asking and responding to fundamental questions about whether or

not such housing facilities are appropriate places for people with disability with high or complex support needs to live.

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**Comment [M01]:** Names of more recent initiative focussed on Boarding houses and hostels?

#### 5. SOME FUNDAMENTAL QUESTIONS

As with any analysis of pressing social issues, fundamental questions need to be a focus to make sense of the intent of possible solutions. We canvassed four different approaches in relation to people's vulnerability and support:

Continue with the status quo where people with disability with high or complex support needs are still found hostel or boarding house accommodation, but with safer and improved quality of housing:

- Regulation
- Standards
- Upgrading of sub-standard facilities

Continue with the status quo where people with disability with high or complex support needs are still found hostel or boarding house accommodation, but with safer and improved quality of housing and some supports employed on site to some identified people:

- Regulation
- Standards
- Upgrading of sub-standard facilities
- Support by hostel staff

Continue with the status quo where people with disability with high or complex support needs are still found hostel or boarding house accommodation, but with safer and improved quality of housing and with supports brought in to some identified people:

- Regulation
- Standards
- Upgrading of sub-standard facilities
- Support by staff from external agency

Consider separately the housing issues of hostels and boarding houses from the lifestyle issues of people with disability living there:

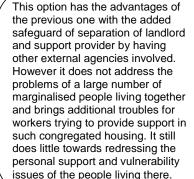
- Address regulation, standards and upgrading in terms of safer, quality housing with the industry
- Address the life context as well as the support needs of individuals with disability with high or complex support needs



Although this option provides for the essential monitoring via regulation and standards for private accommodation, it does nothing towards redressing the support and vulnerability issues of the people living in such places.



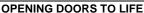
This option has the advantage of option 1 and gives some added support on site. However it combines the roles of landlord and facilitator, the separation of which is an essential safeguard. It provides an institutional service and does little towards redressing the personal support and vulnerability issues of the people living in such places.





By addressing the housing and the people issues separately, the needs of the landlords do not get confused with the personal and lifestyle support needs of vulnerable people living there. Creative personalised connections and solutions could be sought which meet individual needs in a variety of ways, based on exploring what a desirable future might look like with emphasis on reducing vulnerability.





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#### 6. WHAT NEW LIFE MIGHT LOOK LIKE

Home life is neither a recipe nor one particular standard that all people must fit. Therefore there is no single solution for people with disability with high or complex support needs living in boarding houses and hostels. Rather there are as many solutions as there are individuals. Because of this we emphasise a personalised process that becomes a journey towards a new life. It is a process of discovery, trying out, having flexibility to change and doing what it takes to support people to have a decent home with relationships and connections with the wider community.

#### WHAT HOME LIFE SHOULD AIM FOR

Home is having a decent place to live where one has a sense of dignity, safety, security, privacy and with daily personal needs met Being appreciated as an individual and contributing to life in a meaningful way

Having enough money, aside from board, to live life

Having access to the range of housing options available to others including public housing, separate from supports Being safe from abuse:

- Emotional
- Physical
- Financial
- Sexual

Encouraging well being: – hygiene, finances, medication

Having links with the outside world:

- Family
- Friends
- Local community

Having fundamental needs met in a personalised way by having flexible and responsive supports that respect privacy and do not take over life Having rights, with access to advocacy if violated

- As a human
- As a citizen
- As a tenant
- As a service user



#### WHAT COMMUNITY LIFE SHOULD AIM FOR

Community life is about belonging through a range of activities and relationships from intimate commitments with family and significant others, through friends and acquaintances, to local service providers with whom connections are made during the activities played out in everyday life

Connecting with family members and significant others

Seeking hospitality and participating in local community life Linking with needed services: •health

healthfinancial

#### **PROCESS**

Having initial paid support to:

- Develop a trusting relationship with the person with their aspirations being explored and known
- Connect with any significant others in their lives
- Consider short and longer term action that needs to happen to support the person to achieve a decent home life
- Develop ways that aspirations can be achieved including negotiating funding for ongoing and/or episodic supports
- Find housing, and auspice /agency for supports
- Build home life and community connections

Parallel processes of:

- Developing new values based services to support people
- Building community capacity

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#### 7. PRINCIPLES GUIDING PRACTICE

Any work done with people with disability with high or complex support needs living in boarding houses and hostels should be governed by similar intent as embodied in the Principles and Objectives of the Queensland Disability Services Act (1992). It should also be consistent with the vision for the Queensland Government Strategic Framework of "a society that values people with a disability, upholds their rights and supports their equitable participation in everyday life", as well as the commitments of the Disability Services Queensland Strategic Plan.

We feel it is important to restate their intent here so that they do not remain mere rhetoric, but rather become seen as the fundamental building blocks of the work.

## Principles embodied in the Queensland Disability Services Act (1992) include people with disability:

- Having the same human rights and being empowered to exercise their rights
- Realising their individual capacities for physical, social, emotional and intellectual development
- Having services that support their attaining a reasonable quality of life in ways that support their family and their full participation in society
- Participating actively in decisions that affect their lives including development of policies, programs and services
- Having any necessary support and access to information to enable their participation in decisions that affect their lives
- Receiving services in ways that result in minimum restriction of their rights and opportunities
- Pursuing grievances in relation to services without fear of services being discontinued of recrimination from service providers
- Having adequate support to enable pursuit of grievances in relation to services

#### Commitments of the Disability Services Queensland Strategic Plan include:

- Promoting and upholding of rights
- Affording respect and dignity to people with disability
- Empowering people to exercise their rights
- Building strong working relationships with the people themselves and connecting with families and other networks of importance
- Supporting communities in their efforts to work with people with disability to seek local solutions to their needs
- Developing a culture of innovation, flexibility and continuous improvement
- · Providing services that respond to diversity

#### Objectives for service development and provision embodied in the Queensland Disability Services Act (1992) include:

- Focusing on the development of the individual with services designed and implemented to enhance opportunity to establish a quality life
- Focusing on a lifestyle the same as other people ensuring the conditions of everyday life are as close as possible to life valued by the general community and age appropriate
- Coordinating and integrating support services with general services locally which are available to others
- Tailoring to meet individual needs and goals
- Taking into account additional disadvantages
- Promoting competency, positive image and self esteem
- Including people in local community life
- Having no single agency exercising control over the life of the person
- Making information available to person and others in their life
- Ensuring access to independent advocacy support
- Having grievances raised and resolved
- Participating in the planning and operation of services received
- Respecting privacy and confidentiality
- Considering implications for families and significant others



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**Comment [MO2]:** The CRPD, the National Disability Strategy and in alignment of the intent of the NDIS

#### 8. SAFEGUARDING VULNERABLE PEOPLE WITH DISABILITY

Most research, literature and experience acknowledges that in closed, congregated environments vulnerability is usually dramatically increased and endemic in the culture of such facilities. When change threatens such cultures, a backlash resulting in further atrocities can be evoked if care is not taken to safeguard the people involved. We have experienced this with all other attempts at institutional reform and are already aware of some retribution in boarding houses and hostels when people have complained about abuse and other issues, or when advocacy workers have made contact with individuals.

If real change does begin to happen this will threaten the economic, power and authority bases of some owners, operators, staff and residents alike, with fear and uncertainty being important drivers of any backlash. For people who are already vulnerable, whipping up of fear can paralyse attempts to think about a future that could involve positive alternatives, especially when they feel so helpless in their current situation, or especially if they are being threatened. Therefore safeguarding needs to be an integral part of the framework to protect people with disability.

## The vulnerability of people with disability is increased by factors such as:

- having no one who knows the person well, who remains an anchor person in their life, and maintains a long term commitment to them
- having no one who will speak up for the person when it is difficult for them to do so
- having only paid workers who move in and out of the person's life
- being seen as inadequate or dependent
- having no valued adult roles
- being seen as so limited with no gifts or talents of benefit to others
- being given limited opportunities and possibilities to be part of ordinary life
- having no support to participate and contribute to everyday life
- being seen as a problem or a burden to others
- being seen as so different, challenging or menacing and therefore not belonging:
  - o in wider society
  - o in a local community
  - in a family
- being segregated, congregated and/or isolated, away from everybody who is of importance in family and community life
- having lack of tenure or nowhere to live when life is difficult
- having fundamental needs of food, shelter, personal mobility, hygiene, health and safety denied
- · having community membership and citizenship denied
- having human rights denied in abusing or neglectful environments
- · having humanness and individual worth denied
- having life denied.

## **Safeguards**

- Having any support operating from agencies external to the facilities
- Having a worker and an anchor person for the duration of the planning and establishing of new life
- Having processes which focus on who the person is and which build person to person trust
- Having processes which reconnect with and include family or significant others in the person's life
- Working in ways that affirm the person's dignity, rights, well being and competencies
- Having access to external advocacy agencies and right of entry to the person
- Having access to an external authority for grievances and protection if person is victimised or abused.



#### 9. THE IMPORTANCE OF COHERENT, PLANNED CHANGE

For any change strategy to work well, many factors need to be considered. Any processes should separate the boarding houses and hostels owners' and operators' agendas from the agendas of the people with disability and their desire to lead better lives to avoid conflicts of interest. Care needs to be taken to build in the safeguarding process so that people do not suffer backlash or have their lives used as part of political bargaining. A corresponding strategy, which needs to be built in, is a moratorium on backfilling with other people with disability with high or complex support needs so that more people are not put into the situation as others move out.

Overall any work with people with disability should be done sensitively, in direct liaison with them, and in a developmental way with safeguards for them built in.

The strategy put forward in this paper has several components: In general these are:

#### 1. Separating Agendas:

Having industry issues handled separately from those of building new lives with
people with disability with high or complex support needs. The focus of industry
issues would be on the expectations of safe and decent housing for all, worked
out between the housing industry and government, with a separate time frame for
implementation.

#### 2. Immediate Strategies With People With Disability:

- Finding out where people with disability with high or complex support needs are living now, so proper planning can proceed, as to date it is not clear how many boarding houses and hostels there are in Queensland or how many people are accommodated in them.
- Putting a moratorium on Cease any new placement or acceptance of a person
  with disability with high or complex support needs into boarding houses or hostels
  to break the cycle of inappropriate placement
- Safeguarding people involved in change, with access to boarding houses and hostels where it is known that vulnerable people with disability are living now.

#### 3. Short Term Strategies With People With Disability:

- Funding and implementing a developmental process that pilots creative
  personalised alternatives and gives real cost estimates for the building of new
  lives with a broad range of people with disability with high or complex support
  needs currently living in boarding houses and hostels
- Estimating accurate costing of a proper change process and gaining bipartisan commitment to it
- Building local community capacity to include people with disability in the everyday life of their local community
- Developing new ongoing support services and short stay crisis accommodation for people with disability with high or complex support needs with nowhere to live.

#### 4. Longer Term Strategies With People With Disability:

• Allocating tagged funds in a succession of Queensland State Budgets



process could be replicated in any number of institutions as a priority under Qld's NDIS rollout.

**Comment [MO3]:** Planning to move people out of hostels and boarding houses in a strategic manner. This

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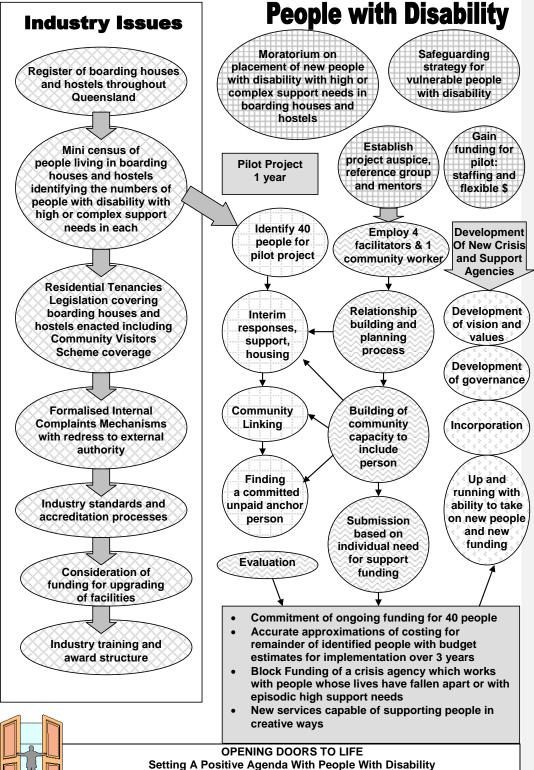
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• Implementing planned change with identified individuals who are vulnerable in their current boarding house or hostel accommodation.



#### 10. A FRAMEWORK OF SUPPORT



With High Or Complex Support Needs Living In Boarding Houses And Hostels



# 11. STRATEGIES TO MOVE A POSITIVE AGENDA FORWARD – INDUSTRY ISSUES

#### 11.1 Register Of Boarding Houses And Hostels ???

The current estimates of boarding houses and hostels vary from 1,200 – 1,400 facilities. The Hostel Industry Development Unit currently has a list of many known ones. As part of local legislation, many City and Shire Councils require registration of institutional residences which house 6 or more unrelated people. It should be a relatively simple process to gain the assistance of Councils to provide a list of the addresses of such residences to begin to compile a register across the state.

#### 11.2 Mini Census Of People With High Or Complex Support Needs

The number of people living in boarding houses and hostels is unknown? with estimates being given between 4,000 and 8,000 residents. No one can accurately estimate how many people with disability with high or complex support needs are in this number, with guesstimates of 2,000 up to 7,000 being put forward. With knowledge of the addresses of boarding houses and hostels, a mini census could be undertaken to establish more accurate estimates. Owners and operators could be asked to state how many residents with high or complex support needs have an ongoing need for others in their lives to provide extra, intentional support above the need of a few extras as part of their accommodation arrangement. Other general, non-invasive information could be sought which might indicate the nature of disability and type of support the person might need, as in a typical census, as well as the cost of board and what it buys. Such information could be used to identify where people are living and in what localities and for the developmental work for new services and building community capacity, as well as to estimate the cost for long term strategies.

#### 11.3 Residential Tenancies Legislation

Currently people living in boarding houses and hostels do not have any legislation to uphold or enforce their rights as tenants. The coverage of boarding houses and hostels in the Residential Tenancies Act has been mooted for many years and recommended in several of the reports, enquiries, projects etc, as well as by the Board of the Residential Tenancies Authority. To date, this still has not eventuated.? Consideration could be given to fiduciary relationships in the legislation to ensure duty of care with marginalised people, or people with disability who have low support needs. Provision should be in the legislation for criminal penalties for offences against residents and civil penalties if owner and operator responsibilities for facilities and safety are breached.

#### 11.4 Community Visitors Scheme Coverage

The Guardianship and Administration Act 2000 gives powers to community visitors to inspect facilities to ensure adults with impaired capacity are safeguarded. The community visitors program is not up and running yet, and regulation would need to be in place before boarding houses and hostels could be considered as visitable

sites under the Act. Definition and prioritisation of sites would also need to be spelt

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**Comment [MO4]:** Does CV visit hostels and boarding houses?

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out in the schedule.

The scheme could have a proactive and reactive role, supporting standards for the accreditation process as well as monitoring the health and well being of residents. The community visitor has the ability to challenge the extent to which a person's rights are being restricted and, amongst other duties, to monitor complaints. They may inquire into and seek to resolve complaints, and make appropriate referrals of unresolved complaints to appropriate entities for further investigation or resolution.

#### 11.5 Formalised Complaints Mechanism

A safeguard of a formal complaints mechanism needs to be developed for grievances by residents, their families or concerned others. The requirements could be embodied in the standards for industry and could be part of, and monitored by, the industry standards and accreditation processes. The complaints mechanism would have internal and external components, and be open to scrutiny, perhaps by being sighted regularly and followed up by the community visitors.

### 11.6 Industry Standards And Accreditation

Industry standards embodying housing, health and safety, and other relevant standards for accommodation facilities need to be developed along with an accreditation process and registration. There would need to be some additional standards, somewhat similar to those of the Disability Services Standards, if people with disability with low support needs were still to remain housed in boarding houses and hostels, which is most likely to be the case. Standards should also embody the fiduciary aspects particularly in relation to the handling of residents' money. Clear "processes with teeth" need to be embodied in the standards and accreditation processes with procedures that direct the closure of substandard facilities.

### 11.7 Consideration Of Funding For Upgrading Facilities and Benefits

As boarding houses and hostels operate in the private sector, many have not been under public scrutiny. Some property owners have not maintained aged buildings and facilities and, if judged, they would be considered substandard. Many complaints relate to safety issues such as electrical wiring, plumbing and drainage, ventilation and fire hazards. In addition maintenance has been let go of kitchens, bathrooms, laundries, lockable areas, floor coverings, furnishings, painting and lighting, so that the cost of refurbishing for many is now high. If a wide range of accommodation is substandard and undignified, then some consideration may need to be given to subsidising facility remodification, if boarding houses and hostels are to remain as one of the budget housing options for marginalised people. In order for some of the facilities to remain economically viable, some assistance similar to other government schemes may also need to be considered. For example if a minimum standard is set for a percentage of the pension which is allowed to be paid for such accommodation, then consideration may need to be given to concessions given in other forms of private or public housing.

#### 11.8 Industry Training And Award Structure



OPENING DOORS TO LIFE Setting A Positive Agenda With People With Disability With High Or Complex Support Needs Living In Boarding Houses And Hostels Comment [MO5]: Any now?

Comment [MO6]: What of this?

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Consideration needs to be given to formalising the training and awards for workers in boarding houses and hostels, so that values based training and practices become the basis for the industry's staff.



#### 12. STRATEGIES TO MOVE A POSITIVE AGENDA FORWARD -PEOPLE WITH DISABILITY

#### 12.1. Putting A Moratorium On Placement Of New People

As with any form of institutional reform, it is important to ensure that change is not undermined by backfilling facilities with the very same grouping of people who are now vulnerable by living there without supports. Therefore a clear government policy needs to be that workers do not seek to place people with disability with high or complex support needs into boarding houses and hostels where their needs cannot be met or where they are vulnerable to neglect, abuse or other dangers. Owners and operators should be informed of this new policy and practice and be discouraged to take in people whose needs cannot be met in this context.

However for such a policy to operate, a crisis strategy needs to be developed to ensure that people with disability with high or complex support needs do have some housing and support when they have nowhere to go. This is not only a cause for concern for this particular group, but also is indicative of the much wider issue of people with disability having such a high level of unmet need with people in crisis situations. The development of a crisis response is discussed further in Section 12.5.1 of this paper.

### 12.2 Implementing A Safeguarding Strategy

As mentioned in the earlier section on safeguarding vulnerable people, a strategy needs to be put in place to ensure the safety and security of people with disability involved in the change process. Safeguards need to focus on three agendas: external paid supports, involvement of significant others from community, and involvement of protection agencies.

Any **support** given to people with disability would need to operate from agencies external to the facilities involved, so that the conflicts of interest are minimised between the support of people and the housing, business and operation of the facility. Workers supporting people with disability would need to hold no allegiance to the owners or operators and be mindful of best interest of vulnerable individuals.

Having a facilitative worker for the duration of the planning and establishing of new life would allow for the development of a personalised relationship between the person with disability and their worker. A key element of the relationship would be a process which focuses on who the person is and which builds person to person trust. This would allow for the individual to become deeply known, have their immediate needs met and their aspirations for future life explored and planned towards.

Any worker would need to work in ways that affirm the person's dignity, address their rights, ensure their well being, both in the short and long term, and build on the person's competencies. They would also need to be creative in finding ways that support a lifestyle that is of the person's own making. As this work may be quite challenging at times, there would need to be the safeguards of initial induction, as well as and ongoing support and mentoring to ensure that they continue to work well

with the person with disability, and on occasions, in the best interest of the individual they are supporting if they are very vulnerable.

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Comment [MO7]: Under the NDIS context there must e impetus in supporting people to make decisions to leave such premises. The 'ownership; and control exerted by managers and owners of boarding houses and hostels is a serious yet invisible form of abuse and control...not allowing visitors onto property, ensuring they are engaged with 'in-house' activities so no external scrutiny is possibe.

**Comment [MO8]:** With any new housing strategy and the NDIS hostels and boarding houses cannot continue to operate as they have been.

As many people with disability living in boarding houses and hostels have lost their family and other social connections, it may be important to have processes which reconnect with and include family or significant others in the person's life. Having **committed others** outside any paid service is well known to be one of the greatest safeguards for vulnerable people. Where this is not appropriate, or where the person is totally isolated, an anchor person could be sought to have a commitment to the person for a minimum of one year to ensure their overall well being.

There maybe times when a person's vulnerability is very high, either because of their isolation, their living situation, the change process, or because they may be very challenging to work with and require great understanding and skill. Having access to **external advocacy** agencies and right of entry to the person may be required so that the person has an independent advocate who is clearly working on their behalf to ensure that decisions are made in the best interest of the person and not in the best interest of the housing or the service.

There may be times when there is a need for access to an **external authority** to follow up on grievances and **to protect an individual** if they are being victimised or abused. This may also be necessary in the wider context where neglect or abuse is happening systematically in the culture of the facility. This will also be important for people with low support needs who remain living there. Proper complaints systems go part way towards safeguarding people, but there are no such mechanisms in most boarding houses and hostels. Even if complaints mechanisms are established, they may be difficult to use if there is an endemic culture of abuse. Access to an external authority to follow up on grievances, especially during the change process will be an important part of the safeguarding strategy. Individually this could be via the Adult Guardian and Public Trust for some individuals and collectively via the Public Advocate until the Community Visitors Scheme is able to operate In this area.

#### 12.3 Funding A One Year Pilot Project

The central strategy for change could be a one year pilot project that establishes a personalised process for working with 40 people with disability with high or complex support needs living in boarding houses and hostels. This pilot could demonstrate ways of working with people to build relationships and plan for, and achieve, a future that has worth, with potential for happiness and a decent life. On the basis of an evaluation of its progress, a long term strategy could be developed and properly costed, which addresses those people with disability with high or complex support needs who remain living in boarding houses and hostels.

A commitment in principle to further work, as part of a long term strategy, would need to be given by the State Government so that non recurrent funds were not put into to the pilot and that any good work is able to be funded to expand and continue.

This pilot is different from the previous Boarding House Project, which focused on outreach support to 60 tenants, including 7 people with disability with high or complex support needs. It does have some similarities in that it works from a community base of flexible planned supports rather than from the traditional case management perspective. This current proposal is based on a model of personalised supports and the concept of doing what it takes to find individualised solutions to the situations that

have led to people with disability with high or complex support needs living in vulnerable situations with inadequate housing and supports.

houses/hostels.

**Comment [M09]:** This is still stymied by the control exerted by the closed and 'underground' nature of boarding

Comment [MO10]: Do they do this?

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The pilot would be auspiced by one organisation and employ four facilitators, working perhaps in two different local communities. Each worker would support 10 people with disability with high or complex support needs living in boarding houses and hostels in the local area. They would have a flexible budget for the duration of the project that would enable responsiveness to the particular immediate needs of individuals whilst the planning and working towards a new life was happening. A fifth community worker would be employed to build community capacity to include people and support the development of a new crisis service and new support services, as well as to coordinate the pilot project.

By the end of the pilot, a submission for funding would be developed with each person based on their aspirations, with costing of the paid supports that needed to be in place to enable an ongoing decent life, with minimised vulnerability.

If it were considered that more than one pilot were to be funded, then the process suggested here could be duplicated in a number of local communities.

**Comment [MO11]:** Did any of these pilots go ahead?

#### 12.3.1 Establishing An Auspice, Reference Group And Mentors

A local, incorporated, community based agency would need to be found to commit to the project for a year as the **auspice** for the pilot. Criteria for selection for such an agency could include having:

- Good credentials and a sound track record
- An articulated values base embodying a commitment to personalisation and social justice for marginalised people
- Good governance and the ability to oversee the work
- Capacity to take on administrative back up of the project.

A key strategy for management of the project would be to establish a **reference group** that would steer the pilot project and oversee the work of the paid staff. The reference group could meet with staff on a monthly basis and report to the management committee of the agency every three months. Composition of the reference group could include people who are:

- Genuinely interested in the well being of people with disability with high or complex support needs
- Understanding of the complex challenges people with disability who have been marginalised, isolated or hurt can present
- Skilled in personalising approaches with people with disability
- Builders of community connections and relationships
- Creative, strategic change agents.

As much of the work done by paid staff would be exploratory and developmental we recommend that a personal **mentor** for each staff member is contracted to spend an hour a month with the worker to discuss their progress. Mentors would have the dual responsibility of professional supervision and personal support, engaging in discussion with the worker to analyse difficult situations or ethical dilemmas in the work they are doing. Mentors would need similar attributes as those described for a

member of the reference group as well as being skilled in working in such a role.

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#### 12.3.2 Employing Workers

Staffing for the pilot would be one community development worker who would also act as the team coordinator, and four facilitators who would support the process of change with individuals. The community development worker would work mainly with people living locally and with identified individuals and groups to develop the capacity to build new connections, supports and services. Facilitators would be working in three different ways, personally with individuals with disability, locally in connecting them with others and systemically to work the system with and on behalf of the individuals they are supporting.

It would be anticipated that the conduct of all project workers would reflect the values, principles and processes put forward in this paper, with the following guidelines for ethical conduct being seen to direct practices in decision-making, especially when issues arise that affect the wellbeing of the people being supported:

- Honouring and respecting the unique needs, values and choices of the person with disability, yet understanding their vulnerability and the importance of safeguards in their lives
- Communicating fully and honestly in the performance of work responsibilities and providing sufficient information to enable individuals being supported, and significant others, to make their own informed decisions to the best of their ability
- Protecting the dignity, privacy and confidentiality of individuals being supported, making disclosure about any limitations on the ability to guarantee confidentiality
- Being alert to situations that may cause a conflict of interest and acting in the best interest of individuals being supported
- Trying to prevent, and promptly respond to, signs of abuse or exploitation, and not engaging as a perpetrator or conspirator of any harm
- Assuming responsibility and accountability for personal competence in practice, continually striving to increase professional knowledge and skills and applying them in practice
- Exercising professional judgment within the limits of the position and collaborating with others, seeking counsel, or making referrals as appropriate
- Fulfilling commitments in personalised ways, in good faith and in a timely manner
- Conducting work with honesty, integrity, and fairness
- Facilitating connections, supports and services in a manner that is sensitive to cultural differences and non-discriminative on the basis of race, ethnicity, creed, religion, sex, age, sexual orientation, national origin, or disability.

Important characteristics of all workers would include:

- Believing in the inherent worth of the person with disability and being loyal to the individuals being served
- Believing in a personalised process that enables the person with disability to develop a vision of a desirable future and move towards its achievement in the context of local community life
- Understanding that the way of working and the relationships that are built are as important as the tangible outcomes
- Having well developed social and communication skills and ability to seek to understand first, before being understood oneself



- Having capacity to facilitate ideas and creative solutions through knowledge, enthusiasm and the ability to build on serendipity
- Knowing the difference between compromise and sell out of people's life dreams
- Knowing the local community and how to access the resources, connections, supports and services it can offer
- Knowing ways of connecting with others, showing hospitality and welcoming people in to the life of a person with disability with complex support needs
- Having mastery of a variety of approaches which strengthen people and encourage their self determination
- Having ability to monitor and evaluate planning and action outcomes
- Having ability to monitor and evaluate personal effectiveness and seek feedback and personal strengthening for oneself.

As both worker roles require deep understanding and skill it is suggested that they be advertised at SACS Award Level 6 for the community development worker/coordinator and Level 5 for the facilitators.

#### 12.3.3 Identifying Forty People To Be Supported

With a pilot project such as this, with an auspicing agency, a reference group and 5 staff, it would make sense to have workers located in relative close proximity to their auspice, perhaps working in two different suburbs in Brisbane where there are high numbers of people living in boarding houses and hostels.

It would be highly likely that several people with disability, with high or complex support needs living in boarding houses and hostels in the local pilot area, would be already known personally to individual advocacy and other human service agencies. Workers would need to talk with advocates and other workers to gain knowledge of where people might be and of some of the issues workers may be aware of. However some people will not have been known or identified, and in some cases, the facilities may not even be known.

An attempt would need to be made to get a register of hostels in the local area so that decisions could be made about where vulnerable people with disability are living with follow up on who could be involved in the project. Agreement in principle would need to have been gained prior to the commencement of the project so that workers could have access to people living in boarding houses and hostels locally. A process where workers are allowed to meet and talk with staff as well as to people with disability themselves would help with the identification of people who are in vulnerable situations and who may need or want to be a part of the project. This would possibly take the first several weeks of the project's work.

Loose criteria for selection of people could be used rather than any formal assessment. Selection could be based on the definition of "people with disability with high or complex support needs who have an ongoing need for others in their lives to provide extra, intentional support above the need of a few extras as part of the accommodation arrangement".

It is anticipated that each facilitator could work with 10 people in a number of different boarding houses and hostels in the local area. This number could be slowly built up



over the first few months of the project as the getting to know each individual, their journey and their aspirations will take time for each person. It would be expected that, by the end of the first six months, the 40 people would have been identified with work towards their personalised futures having begun.

#### 12.3.4 Building Relationships And Beginning A Planning Process

One of the objects of having a facilitator working in a respectful, positive and personalised way with individuals is so that the person with disability is deeply known and that their struggles and aspirations are well understood. Such understanding of the reality of their lives would help in building trust and finding out the essence of who the person is, their experiences, gifts, interests, challenges, hopes and fears.

In general the planning process could assist individuals and others in their life to:

- Discover who they are and how they want to live
- Identify a positive and possible future, based on their vision of future life
- Identify the fundamental things that are essential to the general wellbeing of the person so that dire consequences are avoided
- Establish and strengthen ongoing connections and relationships with significant people in their lives
- Recognise the barriers which stand in the way of achieving their desired future
- Discover ways to overcome those barriers and work towards the desired future
- Develop planning and actions which work towards achieving goals for the future.

Part of the process of support would be to encourage individuals to think about what a desirable future might be like, enabling expression of hopes, fears and preferences which inform the identification of the formal and informal assistance that might be needed to support its achievement. This would be a gradual process based on the development of a relationship of understanding and trust, and put into action at the pace that the person finds comfortable.

For many people who have become isolated, part of the process may involve reconnecting them with families or with other significant people in their lives. However for some this may not be appropriate or it may take considerable time for such contacts to be re-established in positive ways.

Having family and/or other community members involved the person's life can bring a fresh perspective on what might be possible. They may have ideas about discovering opportunities to develop strengths, finding resources or using creative strategies to get things happening without waiting for formal paid services to be involved.

For longer term change, it is vitally important that people's situations continue to be known and brought to the attention of Disability Services Queensland, Housing and wider government, so that political will is generated and appropriate infrastructure responses are put in place. As well, issues need to have the attention of upstanding community members who will get to understand a person's struggles by knowing them, and become personally committed to supporting them and the improvement of their life situation. Workers would need to facilitate such broader processes.

#### 12.3.5 Finding Interim Responses



It is highly likely, during the process of meeting and getting to know people, that some key concerns needing immediate attention will be identified. Some people may have very complex issues that will need urgent creative responses, whilst others may need immediate supports or safeguards to continue living where they are now, whilst planning and work towards a better future is happening. The following scenario gives a real life example of the complexities facing the pilot project's workers.

"Lisa" is in her mid forties and spent her childhood and youth in a large institution. She left approximately 12 years ago without any real life experience, education or support to start a new life in the community. Lisa was brought to the attention of an advocacy organisation because she was sleeping at the local shopping centre. She did not want to go back to the hostel where she lived. She was sharing her room with 2 other people and they had one cupboard between them to store their possessions. The hostel owner had grounded Lisa for a week because she had wet her bed. She said she had been threatened and physically abused.

Lisa spent an exhausting day with an advocate making statements to the police, letting Disability Services Queensland know about her circumstances, finding alternative accommodation and moving to yet another hostel that wasn't really wheelchair accessible, but at least she could get into her room. Not long after Lisa had a fall and was hospitalised. The hostel immediately let Lisa know that she was not welcome back to the hostel and so she became homeless.

Lisa is now living in a caravan park, however she cannot physically access the van, so she lives in a hessian tent that has been erected next to the van. Furthermore, she cannot access the toilet or shower facilities and must use a bucket for all her ablutions. This costs Lisa \$270 a fortnight. She said she would rather live like this than re-enter the private hostel system. Disability Services Queensland, Queensland Housing, the police, the social worker at the institution, the other residents at the caravan park all know about Lisa's circumstances.

After her advocate contacted 10 housing resources including government, community housing and private rental, no accessible housing was available to Lisa. The process to get Lisa listed on priority housing involved lodging the relevant forms, which was difficult for her as she had no possessions and hence no identification. A transfer of the forms from one office to another resulted in the misplacement of the forms for some time, and an OT assessment took a couple of weeks as the OT only works 2 days a week. Now Lisa has the long wait of several weeks or months to actually obtain priority housing.

Obtaining funding for personal support is a long drawn out process, as the Registration of Need and the Priority Rating for funding involves a lengthy, frustrating and usually unsuccessful process. Emergency funds may be an option, however Lisa's current residence in the tent does not meet Workplace Health and Safety standards and consequently this will cause a dilemma for the support agency. Lisa is also reluctant to have workers to provide her personal care as she has had such negative experiences of workers trying to take control of her life in the past......

This situation is clearly not acceptable in today's Queensland society, yet it is not an uncommon scenario. Housing and other supports are neither an entitlement nor immediate, nor is the process non-intrusive and non-judgemental. Financial support is not available so that the necessities of life cannot be purchased. The community does not get to know people, support them, or make them feel valued or accepted.

These sorts of issues will be the real challenges for workers. They will be expected to engage with people to find acceptable solutions when much of the infrastructure to support a decent life is just not there.



As part of the funding for this project, a pool of flexible money is crucial to be used at the discretion of the worker to begin to

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**Comment [MO12]:** I imagine this sort of experience still is typical for some

#### attempt to address the fundamental needs of such vulnerable people.

Flexible money may put in place some stopgap measures that improve quality of life and reduce vulnerability. Other forms of flexible interim funding would continue to be sought from generic sources such as crisis, emergency or support funding from existing agencies. Flexible money would also be needed for other stopgap measures and to begin to explore possibilities for new life.

#### 12.3.6 Linking People Locally

As people with disability with high or complex support needs living in boarding houses and hostels are often leading very isolated lives, it may be important to link people back in with the everyday happenings of their local community. It will be important for workers to be connectors, who know their local community, and can seek out, initiate, and facilitate access to local resources, supports and services that maintain the structure and substance of everyday life.

Connecting people could be supported in two ways:

- with existing formal services such as personalised medical and allied health services, housing, transport, banking, etc
- with informal supports such as family and friends, if they are in the person's life, and the development of new local contacts and networks, especially if the person has no one.

Part of the challenge may be to support the person to find services that will respect them and treat them with dignity and proper concern, as well as finding ways that a person can have informal supports strengthened and/or be welcomed in to new situations where hospitality can be shared. As part of the arrangement with the person, the worker might take an active role in supporting initial connections, being mindful of their role as a facilitator, and stepping back and enabling the person to do this for themself.

#### 12.3.7 Finding Personal Anchors

For people whose lives are very vulnerable, or have no one at all with an interest in their well being, intentional ways to bring others into their lives may need to be explored with the person. Consideration could be given to finding an anchor person, who is a local community member who is prepared to commit some time to an informal relationship on a regular basis for the length of the pilot project, to keep an eye on the person's well being. The status of such a relationship would be friendly and informal and not controlling of the person's life. However it is meant to be an additional safeguard for the person, who, through their relationship, would have someone who is not paid who they can trust and who is genuinely interested in them.

Other strategies might also be considered such as a facilitating the establishment of a circle of support around the person, who would assist the person to work through and take up issues that would lead to getting a decent life.

#### 12.3.8 Preparing Personalised Support And Funding Proposals

Based on the urgent and interim needs of the person, the facilitator would cost the support and other expenditure that the person might need, to

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Comment [M013]: Advocate can only do so much – support workers can have a role here, but under the NDIS LAC's will have an important role in this aspect of linkages. enable some things to be happening immediately and/or in the short term. Funding decisions could be handled in similar ways that emergency funding is handled now, that is from a block budget for that purpose given to the auspicing agency to administer.

Long term personalised funding proposals would be developed and submitted based upon what it would take to work towards the desirable future that the person has considered for themselves. Through the personalised, exploratory, planning process, creative strategies could be costed realistically and reasonably.

#### 12.4 Building Community Capacity

Because the infrastructure to support community based ventures is so poor, the community development worker could be involved in processes that would involve strengthening the local community in its work to include people with disability with high or complex support needs. The approach could be fivefold:

- Seeking out local places where people meet where there is an already existing openness to welcoming people
- Identifying community leadership and supporting their knowledge of the issues faced by people with disability with high or complex support needs living locally
- Identifying community members who have a genuine interest in social justice who
  may be interested in being an anchor person, or involved in a circle of support, or
  in the development of new services
- Investing in the involvement of local people in new thinking, small scale projects and community driven initiatives
- Supporting the informing and lobbying of people in positions of authority to effect change in the lives of people with disability with high or complex support needs living in boarding houses and hostels.

### 12.5 Developing New Services

Under-investment in service infrastructure and social services has happened for many decades, with Queensland being the lowest spending state per capita in Australia. This has been especially so with people with disability with high or complex support needs where spending has been only 58% of the national average. Such a historical legacy has meant that, unless new service infrastructure is built at the same time as money is put into supports for people with disability, the cycle will continue without any development of agencies being able to take on the support.

Many current service providers are not able to take on new clients, nor are they necessarily providing the types of support that people are wanting, with many still operating from an outmoded controlling and paternalistic paradigm. Hence for good support services to be operating, in ways that will support people who have had no appropriate supports, will mean the development of new services. Their development and support would be part of the role of the community development worker.

#### 12.5.1 The Need For Crisis Services

One of the major reasons why people with disability with high or complex support needs end up in boarding houses and hostels is because there are very few services or support initiatives that deal with either homelessness, or crises that

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lead to homelessness, with people with disability. Apart from the fact that supports are rarely in place before crises emerge, most refuges are not physically accessible and, more importantly, they do not have any additional supports that might be necessary to ensure that a person with disability is able to live there with their needs adequately met. Therefore even short term, there is nowhere except a boarding house or hostel.

Disability Services Queensland's preoccupation with huge unmet need and trying to prioritise who should get funding and support before someone else of equal urgency. bears testimony to the fact that anyone with a roof over their head has been thought to be one of the "lucky" ones and not perceived to be in crisis at all.

Therefore one of the crucial tasks of the pilot project would be to demonstrate a personalised model of service provision which is applicable with people with disability whose lives have resulted in a crisis situation of neither having a place to live nor of having adequate supports to meet fundamental need. The process of the pilot hopefully will demonstrate such a model.

Following evaluation, if successful, this personalised model for addressing crisis could be considered for ongoing funding to continue similar work of supporting people with disability who remain inappropriately placed in boarding houses and hostels. The client grouping could also be extended to any others with disability who find themselves in situations where they do not have a place to live with temporary adequate supports. Obviously temporary housing would need to be part of such an arrangement whilst a process of planning for the future was embarked upon.

Part of the community development workers role would be to support the development and establishment of the governance of a new crisis service, embedded in the local community. The plan would be for the new service to take over the auspicing arrangements as an incorporated body in its own right as an ongoing crisis agency working with people with disability.

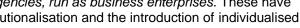
#### 12.5.2 The Need For New Creative Personalised Support Services

Most existing service providers do not have the capacity to take on new clients, especially if an extra 40 people are being considered for supports to be included in a local community. In addition there may be philosophical differences in the nature of the provision of the existing locally based supports. Support services have a history and culture which, given the approach taken in the pilot, may not be able to accommodate such a personalised framework in their agency without huge change.

Examples of the most common forms of current service provision include:

- 1. State government responses, which were originally institutionally based, catering for people with intellectual disability and people with psychiatric illness. Now, after separation of these two groupings and successive waves of deinstitutionalisation, the state's role has broadened to include support of people in many group homes as well as in hospital based and smaller institutions.
- II. Large charities, which were established up to five decades ago by families as an alternative to the big government institutions. Their services now include community based smaller institutions, group homes, day services and some personalised supports.

III. Private for profit agencies, run as business enterprises. These have grown with deinstitutionalisation and the introduction of individualised



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Comment [MO14]: How does this model of service design fit under the NDIS? Should it? The NDIS cannot possibly forestall the need for crisis and emergency services but it is not necessarily the most efficient or effective service model for the state government to own or oversee. Small geographically located emergency responses could present the best solution.

funding arrangements and provide supports in a range of housing types.

IV. Small community based agencies driven by a strong values base of support of active citizenship and ordinary community life, established and governed mainly by families and some people with disability themselves. These are newer locally based developments with the intention of life being played out in the context of committed relationships and the building of valued roles in the local community.

The personalised arrangements of IV would be closest to those suggested in this paper. However the governance would no doubt be quite different, given that many people would not have family members involved in their life, which would necessitate greater embedding in values based leadership in the local community.

#### 12.5.3 Creating Values Based Approaches

For service development to be relevant and sustaining, new services need to operate from a clear values base consistent with the principles and objectives of the Disability Services Act, as outlined in this document. In order to have service provision making the values live through their mission and practices, service development needs to grow a vision for people's lives and from this, the practices that will achieve good outcomes with people with disability. Without growing and revisiting a vision for personalised support with people with disability, services have difficulty in remaining true to their mission and to the people they serve, and tend to operate with a wide range of incoherent practices.

The community development worker would support a steering group in their process of developing clarity about the service vision and mission, and the development of principled policies that would guide practice.

#### 12.5.4 Developing Good Governance And Community Embeddedness

Part of the role of a steering group developing a new service is to establish a coherent framework from which an agency can operate. By the time a new service provider group incorporates, this framework should be clearly in place with people in new governance roles having been preferably involved in, or at least inducted into, the established framework. Clarity about the roles and responsibilities of governance committees also needs to be well understood before the process of gaining funding and employing staff happens.

The developmental process should ensure that some people who already have a clear vision about the positive worth of people with disability and of personalised supports are brought on board. Others could include a few creative and energetic newcomers, opening the way for new experiences and forming part of a journey to develop new service leadership for the future. Hence people with established creative leadership and new enthusiasm make a good mix, combined with personal links to the people being served either by life experience, service, or a sense of social justice.

As this venture is about supporting life in a local community, it makes sense to include a range of members from the local community who have the above attributes. Local understanding of the issues and of the devaluation that people with disability

might face will be important, combined with a clear commitment to providing good service, if the face of the governance of the agency is to



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have people who are well connected locally and who are able to "walk the talk".

#### 12.6 Evaluating The Pilot

The pilot project demonstrates three aspects of working with people with disability:

- A personalised process of identifying and gaining supports that are needed to enable a decent life with people with disability with high or complex support needs
- A personalised process, which, in combination with crisis accommodation, could provide a flexible crisis response with people with disability who are homeless
- A model of developing community infrastructure support, with building capacity to include people, embedding work in the local community and developing new services to support people with disability.

The project could be evaluated in relation to the overall strategy for people with disability with high or complex support needs living in boarding houses and hostels, and in relation to the three aspects that the pilot project has demonstrated. The evaluation could be done by an external agency with an interest in research and without conflicts of interest, yet with an understanding of the intent and values inherent in the project.

#### 12.7 Intended Outcomes

#### **Overall Strategy**

- A framework to advance a positive agenda to address the fundamental lifestyle issues of people with disability with high or complex support needs living in boarding houses and hostels.
  - Clarity about demarcation between the interests of boarding houses and hostels owners and operators, and the interests of people with disability with high or complex support needs
  - Identification of vulnerable people with disability
  - Prevention of backfilling of boarding houses and hostels, with people with disability with high or complex support needs, whose needs cannot be adequately met
  - Establishment of safeguards for people with disability remaining in boarding houses and hostels with access by independent protection and advocacy schemes
  - Ongoing work towards boarding house and hostel industry standards, accreditation and staff training
  - Demonstration of personalised approaches to create desirable futures with people with disability with high or complex support needs
  - Demonstration of ways of working with local communities to develop community based infrastructure to support marginalised people
  - Ongoing funded work towards developing personalised service alternatives with people with disability, which uphold their rights, enhance their quality of life and enable their inclusion in the everyday life of their communities.

#### **Pilot Project Outcomes**

 A personalised process of identifying and gaining supports that are needed to enable a decent life with people with disability with high or complex support needs.

Cessation of, or removal from, abuse or neglect

OPENING DOORS TO LIFE

Setting A Positive Agenda With People With Disability
With High Or Complex Support Needs Living In Boarding Houses And Hostels

- Trusting relationship with a dedicated worker with clarity of who's being served
- Fundamental needs being met
- Engagement in a process of exploration of one's own desirable future
- Re/connection with family or significant others who have a commitment to the person's well being
- Connections with reliable local service personnel for health and other services
- Increased opportunities for engagement in community life
- Increased say in what happens in life
- Safeguards in place to reduce risk and address vulnerability
  - Improved quality of life
  - Supportive mechanisms for staff dealing with complex situations
  - Submission and backup for funding proposal for ongoing paid supports.
- A personalised process, which, in combination with crisis accommodation, could provide a flexible crisis response with people with disability who are homeless
  - Consideration of temporary housing and meeting of emergency needs
  - Outcomes similar to above section for people with disability and staff support
  - Commitment by State Government to move the positive aspects of this proposal forward.
- A model of developing community infrastructure support, with building capacity to include people, embedding work in the local community and developing new services to support people with disability.
  - A method of auspicing which sets clear expectations for work to be done
  - Identification and use of community based leadership
  - Use of strategies which assist community connections, hospitality and welcoming of people with disability with high or complex support needs
  - Identification and use of local service personnel to provide reliable local health and other services
  - Identification of community members with capacity to develop a commitment to the well being of a person with disability
  - Identification and support of community based initiatives that include the diversity of local people
  - Development of values based service provision based in a local community
  - Development of strong governance of small community based agencies.

#### 12.8 Long Term Commitments

It is anticipated that there would be many positive outcomes with people with disability demonstrated in the pilot project as well as a number of demonstrations of good practice in service development and community work. As a result of the evaluation the State Government to could then give commitment to:

- Recurrent funding for ongoing support of the 40 people involved in the pilot project, based on their submissions, and their new support services infrastructure
- Putting forward accurate costing estimates for those people with disability with high or complex support needs still remaining in boarding houses and hostels
- Promising and allocating funding over the next three successive budgets to address the needs of those people with disability with high or complex support needs still remaining in boarding houses and hostels



Comment [M015]: Not congregate care – no matter how it is arranged – (Micah Projects) – people are moved on because of their behaviours (reward/punishment?) and where will they go? What does this say about this model of support for the few who remain? And for those who are removed?

- Block funding of a new crisis agency that works with people whose lives have fallen apart or with episodic high support needs using a personalised process of support similar to those of the pilot project.
- Increasing accessible and other public housing stock
- Providing public housing to be used for temporary crisis accommodation with people with disability with high or complex support needs who are homeless.

Commitment could also then be given, as a matter of course, to encouragement, support and funding of:

- Community based development of new services to support people with disability
- Community capacity building to enable better inclusion of people with disability in local communities
  - Small local agencies that engage in personalised approaches to the support of people with disability and their families.



#### 13. TIMEFRAME FOR IMPLEMENTATION

The timeframe for implementation of the Industry Issues Strategy would need to be worked out between the State Government and the sector players involved in the boarding houses and hostels industry.

The timeframe for the Strategy With People With Disability is considered here.

#### 13.1 Initial Phase

Time	People with Disability	Community	Facilitator	Community Development Worker	Auspicing Agency	State Government	B/House Hostels Industry
July 2001						In principle commitment to pilot and funding of process	
September 2001						Commitment to funding the pilot project	
By January 2002						Moratorium on new placements	Moratorium on new placements



By January 2002	Safeguarding	Commitment of		Commitment of	Agreement to
	strategy in place	advocacy		Adult Guardian,	allow the person
		organisations to		Public Trust and	access to
		continue		Office of the	significant people
		individual work		Public Advocate	in their life, pilot
				as well as	project workers,
				commitment to	and where
				including	necessary,
				boarding houses	individual
				and hostels as	advocates,
				visitable sites for	community
				Community	visitors and the
				Visitors	public advocate

## 13.2 Establishing The Pilot Project

Time	People with Disability	Community	Facilitator	Community Development Worker	Auspicing Agency	State Government	B/House Hostels Industry
By January 2002					Establishment of		
					an auspice, with		
					good value base,		
					administrative		
					supports, office		
					and capacity to		
					do the work		
January 2002					Negotiations with	Funding available	
					the funder about	with guidelines	
					the auspice	and contract	
January 2002					Establishment of		
					a Reference		
					Group to steer		
					project and		
					personal mentors		
					for each worker		



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February 2002				Employment of 4 facilitators and 1 community development worker	Project worker attached	
March 2002		Attend induction	Attend induction	Arrange induction of workers		
March 2002	Meet facilitator	Meet people with disability  Identify people and begin to develop relationship	Meet people with disability			Worker access to boarding houses and hostels to identify 40 people with disability with high or complex support needs

## 12.3 Pilot Project Process

Time	People with Disability	Community	Facilitator	Community	Auspicing	State	B/House
				Development Worker	Agency	Government	Hostels



_					Б.	0 (1)	
From	Being involved in	Growing in capacity to	Supporting a	Building of community	Reference	3 monthly	Cooperating
April	personalised planning	include people	personalised planning	capacity to include	Group meets	meetings	with support
2002			process	people	monthly and		processes
to	Having interim supports	Providing interim	Finding interim		reports to		
March 2003	riaving interim supports	supports	supports	Duilding now obort torm	management committee 3		
2003		зарронз	Supports	Building new short term crisis service	monthly		
	Reconnecting with	Regaining significant	Supporting connections	Clisis service	monuny		
	family or other	relationships	with family or other	Building new creative	Hour long		
	significant people		significant people	support services	mentoring		
		<b>.</b>		embedded in the local	session with		
	Linking with community	Giving everyday	Enabling linking with	community	individual		
	life	opportunity for	community life		workers held		
		hospitality, interests			monthly		
		and service			,		
	Having a committed	Giving personal	Finding a committed				
	anchor person	commitment for one	anchor person				
	and the person	year	0				
	Establishing a personal	,	Supporting				
	vision for future life		development of a vision	Development of sound			
			for future life	vision and values base			
	Actioning plans towards		Supporting and				
	the future	Growing new crisis	actioning plans towards	Development of good			
		service	the future	governance			
	Informing the	Growing new support		Support with			
	submission for funding	services	Developing a	incorporation of new			
			submission for funding	service to take over role			
Manal			for ongoing supports	at the end of the pilot	Fuelveties of		
March					Evaluation of		
2003					pilot process		
					with report to		
					government		



### 13.4 Long Term Funding Commitments Of State Government

Time	Long Term Commitments Of State Government
Committed in Budget 2002	Recurrent funding for individualised support of 40 people involved in the pilot project based on the personalised process of determining need and submitting funding proposals – to begin recurrently when pilot finishes in April 2003
Committed in Budget 2002	Non recurrent funding for the establishment of new crisis service and support services and recurrent funding for some new support service infrastructure to be up and running by April 2003
Committed in Budget 2002	Block funding of a new crisis agency that works with people whose lives have fallen apart or with episodic high support needs using a personalised process of support similar to those of the pilot project to be up and running in April 2003
Committed in Budget 2002	Providing public housing to be used for temporary crisis accommodation with people with disability with high or complex support needs who are homeless to be available by April 2003
Committed in Budget 2002	Increasing accessible and other public housing stock for tenancy by people with disability
Subsequent budget bids	Putting forward accurate costing estimates for those people with disability with high or complex support needs remaining in boarding houses and hostels
Subsequent budget bids	Promising funding earmarked for the continuation of the deinstitutionalisation process with people with disability with high or complex support needs living in boarding houses and hostels.
Committed in Budgets 2003, 4, 5	Allocating yearly funding for the above over 3 successive budgets
Committed in Budgets 2003, 4, 5	Community based development of new services to support people with disability
Committed in Budgets 2003, 4, 5	Community capacity building to enable better inclusion of people with disability in local communities
Committed in Budgets 2003, 4, 5	Establishment of small local agencies that support personalised approaches to the support of people with disability and their families



#### 14. THE COST OF ACTION

The cost of action for a proposal such as this needs to be considered not only in economic terms, but also in social, ethical and personal terms.

In a civil society, it is reprehensible to allow very vulnerable people to live together in large numbers, where they have limited rights, where they are open to abuse, neglect and exploitation, where there is no regulation of the standards of facilities or supports, where fundamental needs cannot be met in a dignified way, where lives are wasted and where some in the industry are making profit from such misery.

Moral conscience dictates that funding must be allocated to redress the situation so that further personal damage is not done to people with disability with high or complex support needs living in boarding houses and hostels.

This paper does not attempt to estimate the economic cost of redressing the industry issues. However an attempt is made here to estimate the cost the pilot project.

#### **ESTIMATED PILOT PROJECT COSTS**

Auspicing agency costs of accommodating workers, phones, transport and other administrative costs @ approx 8.5% of total cost	\$30,000	
4 facilitators to work with 40 people with disability @ approx \$40,000 per worker, SACS Level 5	\$160,000	
1 community development worker/coordinator @ approx \$46,000, SACS Level 6	\$46,000	
Administrative on-costs for workers Holidays, superannuation etc @ approx 19%	\$39,000	
Flexible supports for 40 people @ an average of \$1,500 per person	\$60,000	
External evaluation	\$15,000	
NB These are approximate costs only.  Total Cost	\$350,000	



#### 15. THE COST OF INACTION

A major platform of the Beattie Government, highlighted in the Community Services Strategy, the Queensland Government Strategic Framework for Disability, as well as in the Disability Services Queensland Strategic Plan, has been need for restorative justice to redress the legacy of historical challenges caused by poor infrastructure and lack of service delivery and reform. In particular, this has been acknowledged for those groups who have historical disadvantage in accessing support services as well as by the admission of the under-investment in service infrastructure and social services caused by Queensland having the lowest spending per capita in Australia on social and community services, being only 58% of the national average for people with disability with high or complex support needs.

With recent public outrage over the living conditions in some boarding houses and hostels and the poor quality of life of people with disability with high or complex support needs living there, the three decade legacy must be addressed and not just swept away again with another report, inquiry, task force, project, or bit of money thrown at the sector for cosmetic purposes.

A well-resourced, proper and coherent change strategy is imperative, socially, ethically and personally, not only to restore public faith in the State Government's promises, but also for restorative justice for this very vulnerable group of people, whose lives have been so damaged by long-term government procrastination and inaction.

#### 16. RECOMMENDATIONS FOR STATE GOVERNMENT

#### **INDUSTRY RECOMMENDATIONS**

- 1. Establish an open register of boarding houses and hostels throughout Queensland
- 2. Do a mini census to identify people with disability with high or complex support needs living in boarding houses and hostels
- 3. Enact Residential Tenancies Legislation coverage of boarding houses and hostels
- 4. Gain coverage of boarding houses and hostels as visitable sites in the schedule and priorities of the Community Visitors Scheme under the Guardianship and Administration Act
- 5. Establish the requirement of complaints mechanisms in boarding houses and hostels with redress to external authorities
- 6. Establish industry standards and accreditation processes
- 7. Consider arrangements and funding for upgrading of substandard boarding house and hostel facilities
  - 8. Establish industry training and an award structure for staff of boarding houses and hostels.



#### **OPENING DOORS TO LIFE**

#### RECOMMENDATIONS WITH PEOPLE WITH DISABILITY

- 1. Put a moratorium on placement of people with disability with high or complex support needs in boarding houses and hostels
- 2. Put in place a safeguarding strategy with access to:
  - external paid supports
  - independent advocates
  - staff from protection agencies
- 3. Fund a pilot project for one year to demonstrate:
  - A personalised approach to meeting needs of people with disability with high or complex support needs
  - A possible approach to crisis support and planning towards desirable futures with people with disability with high or complex support needs
  - A model of local community capacity building
  - The development of new personalised support services embedded in the local community
  - Accurate costing of the paid support needs of 40 people with disability with high or complex support needs living in boarding houses and hostels
- 4. Evaluate the pilot project to determine:
  - The helpful and unhelpful aspects of using personalised approaches with people with disability with high or complex support needs to work towards their desirable futures
  - The capacity of personalised approaches to be used as a way of operating for an ongoing crisis agency working with people with disability with high or complex support needs
  - The ability of the model of building local community capacity
  - The ability of the model to develop new, values based, personalised support services
- 5. On the basis of positive evaluation, commit funding to:
  - Ongoing support of 40 people who are currently living in boarding houses and hostels
  - Others with high or complex support needs remaining in hostels in the next 3 subsequent budgets
  - The establishment of a personalised crisis service with access to temporary housing for people with disability with high or complex support needs
  - The establishment of new personalised support services which work towards desirable futures with people with disability
  - Work that strengthens the capacity of local communities to welcome and include people with disability with high or complex support needs
  - Work that develops new personalised services to support people with disability.





Queensland Advocacy Incorporated is an independent, community based systems advocacy and legal advocacy organisation for people with disability in Queensland.

QAI's mission is to promote, protect and defend, through advocacy, the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland.

QAI does this by engaging in systems advocacy work, through campaigns directed to attitude, law and policy change, and by supporting the development of a range of advocacy initiatives in this state.

QAI also provides legal advocacy to people with disability, families and advocates about their legal rights.

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