

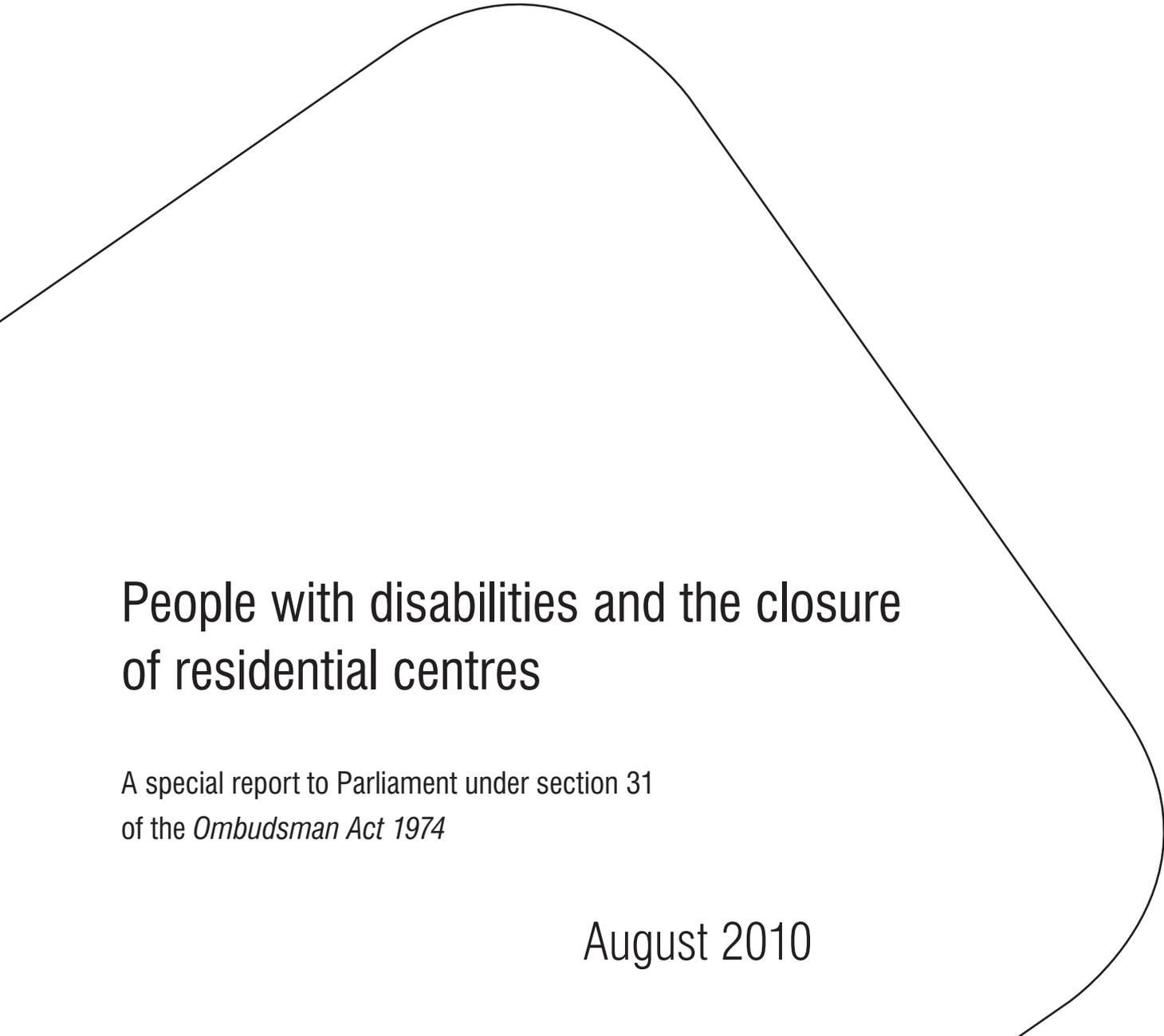


NSW Ombudsman

People with disabilities and the closure of residential centres

A special report to Parliament under section 31
of the *Ombudsman Act 1974*.

August 2010



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Our logo has two visual graphic elements; the 'blurry square' and the 'magnifying glass' which represents our objectives. As we look at the facts with a magnifying glass, the blurry square becomes sharply defined, and a new colour of clarity is created.

NSW Ombudsman
Level 24, 580 George Street
Sydney NSW 2000

General inquiries: 02 9286 1000
Facsimile: 02 9283 2911

Toll free (outside Sydney metro): 1800 451 524
Tel. typewriter (TTY): 02 9264 8050

Web: www.ombo.nsw.gov.au
Email: nswombo@ombo.nsw.gov.au

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August 2010

Level 24 580 George Street
Sydney NSW 2000
Phone 02 9286 1000
Fax 02 9283 2911
Tollfree 1800 451 524
TTY 02 9264 8050
Web www.ombo.nsw.gov.au

The Hon Amanda Fazio MLC
President
Legislative Council
Parliament House
Sydney NSW 2000

The Hon Richard Torbay MP
Speaker
Legislative Assembly
Parliament House
Sydney NSW 2000

Dear Madam President and Mr Speaker

I submit a report pursuant to section 31 of the *Ombudsman Act 1974*. In accordance with the Act, I have provided the Minister for Disability Services with a copy of this report.

I draw your attention to the provisions of section 31AA of the *Ombudsman Act 1974* in relation to the tabling of this report and request that you make it public forthwith.

Yours faithfully

Bruce Barbour
Ombudsman

Foreword

This report is about our work in examining the support for people with disabilities living in ADHC's residential centres.

In examining this issue, we have sought to assess whether the requirements of the *Disability Services Act 1993* are being met. In essence, this legislation requires that people with disabilities have the opportunity to enjoy the same rights and freedoms as the rest of the community.

What we have found is that this is not currently the case for people living in ADHC residential centres. In particular, the evidence from our work has shown that the existing residential centre model restricts the rights and opportunities of the people with disabilities who live there.

Significant action needs to be taken to address this situation. At its core, the closure of residential centres, or 'devolution', is about ensuring that people with disabilities are able to exercise their rights and entitlements, including the opportunity to live full lives and to reach their potential.

While there have been significant developments since the NSW Government's devolution announcement 12 years ago, it is critical that as a community we do not walk away from the commitments that were made to people with disabilities and their families.

Our engagement with the community on this issue has reinforced the importance of providing people with disabilities and their families with a broad range of accommodation and support options, a flexible approach, and meaningful inclusion and partnership in planning for the future.



Bruce Barbour
Ombudsman

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1. Closure of residential centres for people with disabilities

In 1998, the NSW Government announced that all residential centres accommodating people with disabilities would close by 2010. At the time of the announcement, more than 2,000 people lived in these premises.

Today, over 1,600 people with disabilities in NSW continue to live in residential centres, also known as institutions. There are currently 31 residential centres in operation: nine operated by Ageing, Disability and Home Care (ADHC), and 22 by funded services.

A key feature of residential centres is the grouping of large numbers of people with disabilities on one site; the largest centre currently has more than 400 people.

Residential centres are funded under the *Disability Services Act 1993* (DSA), which, among other things, requires services to be provided to people with disabilities in a way that results in the least restriction of their rights and opportunities.

Numerous reports and inquiries have found that residential centres in NSW do not fully conform to the DSA and are incapable of doing so.¹ This is because the nature of institutional care – including the segregation of the centres from the broader community, and the structured and inflexible routines – restricts the rights and opportunities of the people with disabilities who live in these settings.

There is broad recognition that residential centres are outdated models of care, and that they must close. The closure of residential centres is commonly known as ‘devolution’.

In 2006, the Government indicated that the timeframe for devolution had changed from 2010 to closure ‘over time’. The revised approach also included adoption of a wider range of accommodation and support models, including the redevelopment of some centres. *Stronger Together* – the Government’s 10-year plan for improving disability services – commenced the same year, and provided the means for redevelopments to progress.

Since 2006, one ADHC residential centre has closed² and two others are in the process of redevelopment.³ In June 2010, the Minister for Disability Services announced plans for the closure and redevelopment of another ADHC residential centre, to occur over three years.⁴

There are no public plans for the redevelopment or closure of the remaining six ADHC residential centres, accommodating over 900 people. Of the 22 non-government residential centres, public plans are in place for the redevelopment of two of them.⁵

1 For example, Community Services Commission and Audit Office (1997) *Large Residential Centres for People with a Disability in New South Wales* and NSW Legislative Council Standing Committee on Social Issues (2000) *A Matter of Priority: Report on Disability Services*.

2 The Grosvenor Centre closed, with residents moving to two 10-bedroom houses on the same site, designed as specialist support for people with complex health needs.

3 The Peat Island Centre will close this year, with the development of four five-bedroom houses in the community in Wadalba, and an aged care village for 100 people at Hamlyn Terrace. The Lachlan Centre will also close this year, and all residents will move to 10 five-bedroom houses built in a different part of the same site, designed as specialist services for people with challenging behaviour.

4 The Riverside Centre will be redeveloped, and replaced by: 1) a specialist supported living cluster on-site for people with challenging behaviour; 2) five community-based houses for people with additional care needs, located close to the cluster; and 3) 40 houses across the Western region for people not requiring specialist support.

5 Ferguson Lodge, operated by Paraquad; and Weemala, operated by Royal Rehabilitation Centre Sydney, will be redeveloped, with new accommodation to be built on the current sites.

2. Community forum on devolution

In June 2010, and in partnership with the Disability Council of NSW, we held a one-day forum to discuss progress in closing residential centres, and the related challenge of providing options for people with disabilities to live their lives to the full within the community.

The forum was attended by close to 300 people, comprising a broad mix of people with disabilities, family members, service providers, advocates and government representatives.

ADHC reported to the forum on the current status of devolution. A panel of people with disabilities and their representatives discussed their experiences in moving out of institutions. Another panel, of service providers, staff and a researcher, talked about what it takes to successfully deliver community-based support, as well as the challenges, opportunities and priorities as we move forward.

The forum allowed for the exchange of a diverse range of views on devolution. In the midst of differing opinions, however, there were a number of strong themes that emerged:

1. **People with disabilities need to have direct and meaningful involvement in discussions about devolution and planning for the future.**

Discussion at the forum reinforced that devolution is not about plans and promises; it is about people.

People with disabilities who are leaders in the sector communicated strongly at the forum that we need to retain focus on the fact that the push to close residential centres originated with the residents of those centres. At its core, devolution and the move to community-based living is about people with disabilities having the same rights, opportunities and freedoms as everyone else. Speakers and participants were clear that people with disabilities living in residential centres must be at the centre of planning for the closure of those centres and what follows, and must be supported to have meaningful and direct involvement.

2. **There needs to be respect and support for, and proper engagement with, families.**

What also came through strongly in the forum was the need for ADHC and government to ensure that the families and other representatives of people with disabilities living in residential centres are brought along as we move forward with devolution. Families need to be shown respect, engaged in the discussions, and provided with information and support to enable them to be confident that the health, safety and wellbeing needs of their family member will be met in the community.

A number of family members at the forum also highlighted the lack of supported accommodation options for adults with disabilities living with ageing parents in the community.

3. It is critical that people moving out of residential centres have adequate and appropriate support in the community.

Participants were united in acknowledging that change must deliver better outcomes and quality of life to people with disabilities who move into the community.

Participants noted the basic need for increased and appropriate funding to successfully deliver community-based living. This was particularly important in order to ensure that support provided to people moving into the community is person-centred. Support must be designed to meet the particular needs of individuals, and more power should rest with people with disabilities and their families, rather than with service providers.

The emphasis on ensuring that people with disabilities moving out of institutions receive adequate and appropriate support in the community is critical to the success of devolution and the delivery of better outcomes for individuals. It relates to the availability of existing community-based services, the funding and delivery of specialist disability services, and the relationship developed by the individual to the community.

4. Living in the community is not the same as community inclusion.

Participants reiterated that devolution must recognise that community living is not just about bricks and mortar. It is about individuals being part of the community, maintaining strong links with their families, and being able to build valuable, meaningful relationships and connection with their community.

5. There needs to be greater access to advocacy and information.

Access to independent advocacy support for people living in residential centres was seen as extremely important, to ensure that individuals are involved in planning and decisions. There was also a consistent view at the forum that more information needs to be provided to people with disabilities and their families on proposed plans for devolution, the options available, and the intended transition process. Families need support, and would benefit from contact with other families who have been through the devolution process.

We note the recent release of a useful DVD by Greystanes Disability Services⁶, *A place to call home: talking about devolution*, designed as a resource to assist with discussing devolution and to share the experience of residents, families, and staff in the devolution process.

6. People in residential centres should be assisted now.

Some participants pointed to the need for increased resources for existing residential centres to improve the services and support currently being provided, and noted that many of the centres have become run down over the years due to a lack of funds and the continuing state of limbo while waiting for devolution plans.

⁶ Greystanes Disability Services is now known as Disability Enterprises. In the late 1990s, Greystanes Children's Home, a large residential centre for children and young adults with disabilities and complex health needs, closed. The children and young people moved into houses in the general community.

7. One model of housing and support does not suit everyone, and the focus needs to be on individuals.

The forum agreed that people with disabilities and their representatives need accommodation and support options in order to exercise choice. To provide choice, there needs to be greater diversity of accommodation and support options, not just group homes. Participants pointed to the need for self-directed funding; inclusion of people with disabilities in affordable housing and social housing options; and shared equity and partnership arrangements.

A number of family members also highlighted the lack of available supported accommodation options for adults with disabilities living with ageing parents in the community. These families similarly emphasised the need for partnerships, greater choice, and certainty, and the importance of appropriate community-based support.

The message of forum participants regarding the need for increased accessibility, flexibility and choice of accommodation and support options has been consistently raised across the disability sector for some time. In 2006, the Government's *Accommodation and Support Paper* and subsequent 10-year plan, *Stronger Together*, clearly reflected the message of people with disabilities and their representatives that 'one size does not fit all'.

In this context, ADHC developed an Innovative Accommodation Framework, released in its *Innovative Accommodation Support Options for NSW* paper in January 2009. The Framework outlines 12 different accommodation models that will operate in NSW for people with disabilities, including group homes; villas and apartments; cluster, village and co-located models; and flexible packages.

ADHC has indicated that it is looking at how the whole disability accommodation sector can gradually move into alignment with the Innovative Accommodation Framework. This includes using *Stronger Together* funds to build new innovative models of accommodation support, and replacing existing properties that are no longer 'fit for purpose', such as residential centres.

Amongst other key developments, the first four years of *Stronger Together* has enabled an expansion in the availability of supported accommodation, progress in the closure and redevelopment of some ADHC residential centres, and the commencement of some innovative accommodation and support options. From the devolution forum, it is evident that the second half of *Stronger Together* needs to build on this work and expand the range, availability and flexibility of options.

3. Our work in relation to ADHC residential centres

Since this forum, we have carefully considered these very clear messages against the background of substantial work we have done in the past two years looking at key aspects of the operation of ADHC residential centres.

In particular, we have been examining the extent to which people with disabilities currently living in residential centres operated by ADHC are receiving services that are in line with the DSA. The clear intention of the DSA is to ensure that people with disabilities in NSW have the same basic rights as other members of our community.

These include fundamental rights that most of us take for granted, such as:

- to live in and be part of the community;
- to reach our full potential;

-
- to choose the way we want to live our lives; and
 - to participate in decisions that affect us.

The DSA requires services to make sure these rights are upheld. This includes making sure that the services they provide to people with disabilities meet their individual needs and goals.

In 2008, we reviewed ADHC's actions to identify and meet the individual needs and goals of 60 people with disabilities living in nine residential centres. We released our final report from that work, *Review of individual planning in DADHC large residential centres*, in June 2009.

Our review identified that important needs of people with disabilities living in ADHC's residential centres were not being met, which impeded their fundamental human rights. These included the right and opportunity to communicate with others and make decisions and choices; to participate in the community, and to develop social networks; and to develop skills to increase independence.

In effect, this meant that the ability of those individuals to have control over their own lives and to fulfil their potential was significantly restricted.

We found that ADHC residential centres did not fully conform to the DSA in critical areas. Of particular significance, we found that people with disabilities living in those centres:

- received services in a way that placed restrictions on their rights and opportunities;
- did not have access to advocacy support where necessary;
- had lives that were very different to those valued in the general community; and
- had all, or most, aspects of their lives controlled by one service provider.

We recommended to ADHC that it should develop a comprehensive action plan, detailing the steps it would take in the next 12 months to attempt to address the problems and the issues we had identified.

Attached to this report is a detailed analysis of the adequacy of ADHC's response to our recommendations. In summing up ADHC's response, we make the following observations.

ADHC has taken action in each of its residential centres to improve its capacity to meet the individual needs and goals of residents, and it is clear that staff are making a genuine attempt to improve outcomes for people with disabilities living in these centres. Actions have included extensive staff training; development of resources to assist staff; changes to improve individual planning systems and staff accountability; and greater access to advocacy support for some residents.

However, in the main, outcomes for people with disabilities living in ADHC's residential centres do not seem to be significantly different to what they were over 12 months ago.

The strategies put in place by ADHC to address our concerns are largely focused on improvements to existing processes and activities within large residential centres. However, our work, and our consultations with relevant agencies and advocates in contact with residents, has indicated that ADHC is still unable to ensure that the rights of people with disabilities living in its residential centres are being adequately met.

People with disabilities in these centres still appear to be infrequently involved in making decisions, particularly about how they want to live their lives, and how they want to be supported to do so. We found that residents are encouraged to make simple choices about items such as clothing or type of drink, but have limited opportunity to be involved in more significant decisions, such as where they want to live, or who they want to live with.⁷

⁷ In facilitating the meaningful involvement of residents in more significant decisions, we note the importance of augmentative communication, advocacy support, and clear guidance and assistance for staff.

The capacity of the residential centres to afford opportunities to residents to develop their skills and increase their independence does not appear to have changed. Opportunities continue to be constrained by the institutional model of accommodation and support. For example, the provision of pre-packaged meals means that there are limited opportunities for residents to cook. Other restrictions include set times for meals and other activities, choice within a limited set of options, and restrictions pertaining to staff availability and roster. The residential centre model of accommodation and support also hinders the meaningful physical and social inclusion of residents in their local communities.

Advocates report that existing opportunities, such as assisting residents to build living skills ahead of their move into new accommodation (for those centres under redevelopment), are not being taken up.

ADHC is changing the way that it undertakes planning to meet the individual needs and goals of people with disabilities. It is moving to person-centred planning, where the person with a disability has greater power and control in planning the life they want to lead. As it stands, the existing model of service delivery in ADHC's residential centres is in conflict with person-centred planning principles.

4. Conclusion

This report raises fundamental issues about how people with disabilities in residential centres live their everyday lives.

The concerns and solutions canvassed in our forum on devolution, and the issues identified through our work on individual planning, raise significant questions about how residential centres can provide people with disabilities the same basic rights, freedoms and opportunities that people living in the community have, and rightly expect.

We have seen evidence that ADHC has, and is, working to improve practice and service delivery in its residential centres. This is important and necessary work. However, because of the restrictions and constraints inherent in the residential centre model, it is most unlikely that people in these centres will ever be able to fully exercise individual choice and participate as full members of the community.

The strong body of research supporting the Government's initial commitment to devolution and the movement of residents in these centres into the community is grounded in the need to ensure that people with disabilities are given a fair go to live their lives to the full, just as people do in the general community.

In essence, this is what the DSA commits this State to, and whether we meet this challenge is a test as to whether we have a commitment to the fundamental human rights of people with disabilities living in these residential centres.

As stated by Andrew Buchanan, the (then) Chair of the Disability Council of NSW, at the devolution forum, 'We must reignite enthusiasm for the policy that residential centres will close. It is the right policy for our time. NSW has unfinished business to complete, so let's get on with it.'

Recommendations

1. In providing advice to the Government regarding *Stronger Together 2*, ADHC should make clear the need for:
 - a) detailed plans to deliver on the devolution commitment;
 - b) adequate funding to meet this commitment; and
 - c) effective strategies to ensure that there is meaningful consultation and partnership with people with disabilities, their families and other representatives, in the devolution process.
2. Until devolution occurs, at the beginning of each year ADHC should provide a report to this office on its actions to:
 - a) progress the closure of the remaining residential centres;
 - b) ensure that people with disabilities living in the residential centres, their families and other representatives have meaningful and direct involvement in the planning for the closure of those centres; and
 - c) progress the implementation of the action plans for Metro Residences, Hunter Residences and Riverside.

Appendix 1:

ADHC's response and progress

We released our *Review of individual planning in DADHC large residential centres* report in June 2009. In that report, we recommended to ADHC that it should develop a comprehensive action plan, detailing the steps it would take in the next 12 months to address the issues identified. We indicated that the action plan should clearly articulate how agency would:

- improve individual planning;
- foster resident involvement and participation in decisions and choices;
- increase the independence of residents;
- foster relationships and community integration; and
- ensure compliance with ADHC policy.

Under the above areas, we asked ADHC to indicate how it would address a range of specific issues we had identified in the report.

At the time of our report, ADHC had started a review of its *Individual Planning* policy. Consequently, we also recommended that the agency consider our findings in that review.

Given the extent of the concerns we had raised in our *Review of individual planning* report, we have closely monitored ADHC's response to the report's recommendations over the past year.

In response, ADHC has provided separate action plans for Hunter Residences, Metro Residences, and Riverside.⁸ The initial action plans included a report of progress as at 31 July 2009. ADHC provided additional reports of progress as at December 2009 and June 2010.

We have analysed these reports to assess the adequacy of the action taken. We have also considered information about individual planning that we have gleaned from our reviews of the deaths of 18 residents of ADHC residential centres between October 2009 and June 2010.⁹

We have also consulted a number of parties currently in contact with people with disabilities living in ADHC residential centres, including Official Community Visitors; the Public Guardian; and advocates from the Western Sydney Intellectual Disability Support Group, People with Disability Australia, and the Disability Information and Advocacy Service.¹⁰

Action to improve individual planning

We asked ADHC to tell us how it would:

- improve the quality of Individual Plans (IPs);
- ensure IP goals are implemented and action is taken to address barriers to implementing goals;
- identify and address the unmet needs of residents, including accommodation needs and unmet needs identified through lifestyle and environment reviews;

⁸ Following its redevelopment, ADHC no longer considers Grosvenor to be a residential centre, and, as a result, it is not included in the action plans.

⁹ Our reviews of the deaths of people with disabilities in care are conducted pursuant to Part 6 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*.

¹⁰ For simplicity, in the report we have referred to all of these external parties as 'advocates'.

- ensure that IPs are reviewed; and
- effectively monitor and oversight individual planning.

What has been done

All of the residences have focused on training and re-training staff at all levels, with the aim of improving the quality of IPs and staff understanding of individual planning and its link to service delivery. Staff training has been a particular focus at Riverside, with 'Back to Basics' training and mentoring provided to all staff to improve individual planning and support to residents and to change staff culture.

Other key actions targeted at improving individual planning include:

- revision and development of staff resources; such as workbooks, guides and examples;
- creation of positions/teams in some residences that are focused on improving the quality of individual planning, including an IP Team at Rydalmere/Westmead and an IP Committee at Hunter Residences;
- incorporation of individual planning quality and progress into supervision, team meetings, and regular reporting; and
- improved systems for scheduling and monitoring IP planning, meetings and reviews, and tracking progress.

In the main, advocates told us that they have seen some improvements in the quality of IPs, particularly at Riverside and Rydalmere/Westmead. They associated the improvements with staff training, as well as increasing numbers of new staff at Riverside, changes to the IP process at Hunter Residences, and creation of the IP Team at Rydalmere/Westmead.

There have also been some changes in relation to identifying and addressing barriers to implementing goals. For example, Hunter Residences has modified its IP template so that staff are now required to consider potential and existing barriers to residents achieving their goals.

Our assessment

The focus on individual planning in the core work of staff is an important development, and we note that the residences have taken steps to ensure that staff training is reinforced, and actions and progress are monitored.

However, considerable work remains to be done to lift the quality of the plans and goals for each individual. For example, there are still problems with some of the goals that are set in IPs. In the 2009/10 IPs that we examined, we noted many goals were:

- focused on service tasks: 'develop lifestyle plan indicating use of cream/gauze';
- broad, with no guidance as to how to implement them: 'to encourage _____ to have choice';
- focused on the status quo: 'to maintain _____'s health status by having access to all appropriate specialists'; and
- without any clear meaning: 'morning tea'.

Reviews of IPs now appear to be occurring on a regular basis, and residents or their representatives are increasingly in attendance. However, the reviews do not tend to result in any change or revision of the IP, irrespective of whether the goals have been achieved or not. Timeframes for goals appear to be 12 months, regardless of whether the goals could be achieved more quickly.

Work to comprehensively identify the unmet needs of individuals and link these needs to IPs has not significantly progressed. For example, one of the issues that we reported in 2009, was that individuals were living in accommodation that was unsuitable for reasons such as space, comfort, privacy and compatibility, and that these needs were rarely identified or addressed. However, in its action plan in response to our report, Riverside failed to make any reference to addressing accommodation needs in the future IPs of its residents. By contrast, the other residential centres have designated people to take responsibility for managing accommodation changes, but no details have been provided concerning any outcomes achieved on this front.

Action to foster resident involvement and participation in decisions and choices

We asked ADHC to tell us how it would:

- provide clear information and support to residents to enable them to understand the individual planning process;
- ensure that residents are active participants in their individual planning process, including the planning for their IP meeting, and consultation on their needs, goals and wishes;
- foster and facilitate residents' participation in decisions affecting their lives, such as the planning and operation of their services;
- ensure that residents have access to advocacy support where necessary;
- clearly identify the communication needs of residents and ensure that these needs are met;
- ensure that day program service provision for individual residents is informed by their needs, goals and wishes, and linked to their IPs;
- ensure that ADHC does not exercise control over all or most aspects of the lives of residents; and
- provide services in a way that results in the least restriction of residents' rights and opportunities.

What has been done

- Rydalmere/Westmead has developed and implemented a program called *Your Planning Meeting* – this seeks to provide accessible information to help people with disabilities understand the IP process, and help staff with their discussions with the resident around the development of the plan. This centre is also exploring a number of other strategies to gain client input into IP goals, including consideration of how to enable people with severe to profound cognitive impairment to have meaningful input.
- The Disability Information and Advocacy Service (DIAS) now advocates for people living at Riverside who do not have family or other support. DIAS is also included in a Disability Practice and Review Group that Riverside has set up to improve services and support.

- Riverside has contacted Self Advocacy Sydney in relation to education and support to develop a self-advocacy group and increase individual advocacy skills.
- Metro Residences has set up advocacy databases to identify residents without family or other support who need to be referred to an advocacy service.
- There has been action taken to identify the communication needs of individuals in Metro and Hunter Residences.
- The links between the day program and the IP have also been strengthened, with day program staff regularly attending IP meetings. For example, Rydalmere/Westmead is exploring a number of strategies for increasing the input of residents into their day program activities and options, including client meetings, varied communication systems, and work with speech pathologists.

Our assessment

Involvement in the individual planning process

Outside of Metro Residences, there has been little progress to enable residents to understand, and have meaningful involvement in, the IP process.

The action plans include a commitment that residents will be supported to be involved in their IPs, but provide scant details as to *how* this will be done. Identifying how staff will facilitate the meaningful involvement of people with severe or profound cognitive impairment in individual and service planning appears to be a significant challenge for the residential centres. It is not clear from the action plans how this will occur.

While action has been taken to identify the communication needs of residents, there has been little progress in relation to ensuring that these needs are met – such as building in the use of augmentative communication as part of everyday interaction. On this issue, advocates have reported to us that progress towards meeting the communication needs and goals of individuals tends to be slow.

From our review of 2009/10 IPs, we noted that plans tended to reflect greater staff recognition of the link between improving communication and improving the individual's ability to make decisions and choices. However, we found that the timeframe set for completing communication-related goals tended to be 12 months; progress was not always evident; and the IPs for some people noted challenges in ensuring staff action to use the tools or communication aids once those tools were developed.

Advocacy

There has been action taken to improve access to advocacy support for some residents, particularly at Riverside. We note that Riverside and Metro Residences seek advocacy support for people who have been identified by staff as not having any family or other support.

However, we are aware that although there are many residents whose family involvement is minimal, many of them do not seem to be currently considered by ADHC for advocacy support.

We are particularly concerned about the limited progress towards improving access to advocacy support for residents of Hunter Residences¹¹. While the progress reports indicate that staff sought advocates for a number of residents at the Peat Island Centre, no further information has been provided regarding advocacy for residents in Hunter Residences.

¹¹ Stockton, Peat Island, Kanangra and Tomaree Centres.

We also note that ADHC's response to our draft report in April 2009 stated that funding for advocacy services for people with disabilities in residential centres 'is considered in the [large residential centre] redevelopment program'. No further information has been provided about this.

Advocates have told us that very few residents are linked in to advocacy support. They have also advised us that it can be difficult for them to get adequate information about individuals prior to the IP meetings, and that this compromises their ability to provide effective advocacy.

Involvement in decisions about how services are planned and delivered

There continues to be little involvement by residents in the decisions made about the support that they receive. However, there are:

- client meetings in some residences/units;
- a resident group at Rydalmere/Westmead that is involved in decisions regarding menus and on-site social events; and
- Riverside reports that residents are represented in its new Disability Practice Review Group.

Despite these initiatives, the opportunity of individuals to have a say in how they want to live their lives, and be supported to do so, is limited. Strategies identified in the action plans for gaining the involvement of the person with a disability in service planning tend to focus on families and other stakeholders. We noted in our review of 2009/10 IPs that, even where a goal in the plan was aimed at increasing the person's involvement in decision-making, opportunities for involving the resident in the planning and delivery of their services did not appear to be taken. For example, involvement in the planning for their move to new accommodation as part of the devolution process.

Since our review, there appears to be an increased focus on improving the involvement of residents in making simple choices, with many of the IPs we reviewed including goals related to this. In the main, the choices relate to set options, such as choice of drinks or items of clothing. While this is not unreasonable as a starting point for residents with a severe or profound cognitive impairment, there is no indication as to how residents will be supported to be involved in more significant decisions, such as where they want to live, and who they want to live with.

The restrictions in, and inflexibility of, services to people with disabilities in the residential centres remain, including set times for meals and other activities, choice within a limited set of options, and restrictions pertaining to staff availability and roster. The residences' action plans do not adequately indicate how they would ensure that their services are provided in a way that results in the least restriction of residents' rights and opportunities on a day-to-day or long-term basis.

Action to increase the independence of residents

We asked ADHC to tell us how it would:

- provide opportunities to individuals to learn and practise life skills that promote independence;
- improve the involvement of residents in meaningful activities;
- ensure that the conditions of everyday life of residents are the same as, or as close as possible to, norms and patterns that are valued in the general community; and
- improve accessibility for residents using wheelchairs.

What has been done

- Riverside is developing a pilot project to establish a training and development unit to prepare residents for transition to the community.
- Lachlan staff will conduct a 'Basic Life Skills' assessment to identify residents' skill levels and needs.
- Metro Residences has incorporated discussion of residents' involvement in meaningful activities into the agenda of unit and nurse manager meetings. Separate key performance indicators relating to meaningful activities have been developed for each unit at Lachlan, based on the needs and preferences of individuals.
- Trainers and external presenters attend day program meetings at Rydalmere/Westmead on a quarterly basis to develop staff skills in engaging clients in meaningful activities and active participation. The recreation service at Rydalmere/Westmead has been extended to provide weekend and evening community-based activities.
- Social Role Valorisation training is being provided to Riverside staff.
- Hunter Residences has conducted a condition and compliance audit of all of its facilities, and work is underway to reduce the gaps in compliance.

Our assessment

Substantial work needs to be done to identify and provide opportunities for people with disabilities living in residential centres to develop and maintain skills to increase their independence, and to build these opportunities into daily life.

Residences have placed a heavy reliance on the IP process to identify skills gaps and existing opportunities. However, outside of the functional skills assessment at the Lachlan Centre, it is not clear what information feeds into the IP process to enable residents or staff to identify existing skills, potential skills-related goals, or opportunities for residents to increase their independence.

In our review of 2009/10 IPs, we noted increased references to skills and independence, but found little reflection of this in practice. The emphasis tended to be on skill maintenance rather than skill development, and it was not clear how staff had identified the person's existing skills and capacity or what skills the person wanted or needed to focus on.

Advocates reported to us that opportunities for skills development are not being taken up, and staff perform most of the tasks and daily living activities *for* residents rather than with them. Advocates told us that the planned transition of some residents to new accommodation may have presented a useful opportunity to work towards increasing their independence ahead of the move, but they have not seen this in practice. Advocates also advised that the residential centre model of accommodation reduces available opportunities for residents to increase their living skills. For example, cooking opportunities are reduced through the delivery of cook-chill meals.

The information contained in the action plans does not clearly indicate how the residential centres will work towards the goal of making everyday life of residents the same as, or as close as possible to, the life experienced by those in the general community. The stated actions are largely focused on making sure that staff know about the rights of people with disabilities and the disability services standards. While this is a useful starting point, it does not address the existing factors in residential centres which lead to the everyday life of residents being very different to the rest of the community. This includes set routines, shared bedrooms (with up to three other people), little privacy, and limited decision-making rights – from who residents live with to what they do on a daily basis.

Action to foster relationships and community integration

We asked ADHC to tell us how it would:

- promote and support the participation and integration of residents in their local communities, including increasing the amount of meaningful involvement of residents in community-based activities and programs; and
- support residents to develop social networks.

What has been done

- Hunter Residences is reviewing resource booklets in all of its centres regarding community activities and services.
- Metro Residences is promoting participation of residents in their local community through visits to family, sporting activities, holidays, vocational courses and the use of external services.

Our assessment

The action plans have focused on increasing community participation and contact, and our review of 2009/10 IPs generally indicated increased attention in this area. Advocates told us that there have been improvements for some residents in the frequency and quality of community access, including the inclusion of more creative options. However, advocates also indicated that community access activities are largely focused on outings, with little emphasis placed on increasing opportunities for independence.

Broadly, the residential centres have identified the involvement of residents in sporting activities and competitions and linking in with existing community events and groups, as key strategies for supporting community integration. In relation to supporting residents to develop social networks, the action plans focus on increasing contact with community groups and maintaining existing relationships.

In practice, it is not clear how the physical and social integration of residents into their local communities will occur. The challenge is how to move from community *contact* to *integration*, and the action plans do not adequately address this.

By virtue of the model of accommodation and support that residential centres provide, there are particular challenges in facilitating community integration in relation to people with disabilities living in these settings. In fact, some of the critical elements that help support successful integration and community connectedness are in conflict with the nature of life in residential centres, including:

- residents being physically separated from the community by the location of the centres. (The residences are generally isolated from the local community, including three centres – Lachlan, Kanangra and Riverside – situated in the grounds of psychiatric hospitals);
- the congregate nature of the residential centres – including large numbers of people with disabilities on one site, little private space, and often shared bedrooms – which does not lend itself to individual residents inviting people over or the building of social contacts and relationships with those outside the centres; and
- the way in which services are typically delivered – with set routines, restrictions on personal freedom and autonomy, and an emphasis on the group rather than the individual – works against residents developing relationships and social networks.

Factors affecting ADHC's ability to meet individual needs

In our *Review of individual planning* report, we outlined a number of factors that were affecting the ability of staff to meet the individual needs of people with disabilities living in ADHC residential centres. These included inconsistent access to allied health and psychological services; staffing constraints and gaps in staffing; and restrictions related to living in a congregate environment.

Information indicates that there have been some improvements relating to access to services, particularly in the provision of behaviour intervention and support at Riverside. There have also been increases in staffing in some critical areas, such as day programs at Rydalmere/Westmead and Hunter Residences, and overall staffing at Riverside.

However, staffing constraints and gaps continue to exist and adversely affect residents. Advocates reported that staffing levels are a problem, and make it difficult for staff to provide support beyond meeting daily needs. Advocates told us that resource constraints across the residences means that it will be difficult for ADHC to deliver real change to meaningfully address the issues in our 2009 report.

The impact of staffing constraints on the lives of residents was reflected in our review of 2009/10 IPs.

Issues related to congregate care

Our review of 2009/10 IPs identified a number of areas in which the congregate care environment of the residential centres adversely affects residents. In addition to continuation of the restrictions outlined in our *Review of individual planning* report, we noted:

- References to individuals developing behaviour problems as a result of congregate care, including:
 - a woman who reportedly developed defensive behaviour and repeatedly absconded in response to being in threatening situations in a previous residential unit; and
 - a woman who engaged in self-harming behaviour due to living in dormitory accommodation with a large number of people, and who was noted to be much better after moving into smaller, more personalised accommodation and support.
- Individuals being upset by the level of noise in the congregate environment, demonstrating challenging behaviour in noisy environments, or not being suited to their current accommodation because of the noise of their co-residents.
- Repeated references to individuals not having any relationship with, or interest in, other residents – either preferring to keep their own company or to interact with staff.

Move to person-centred planning

In October 2008, ADHC announced plans to review its *Individual Planning* policy, with the aim of moving towards reflecting the contemporary practice of person-centred planning. In this context, we recommended that ADHC ensure that the findings in our *Review of individual planning* report be considered in its review of the policy.

Lifestyle Planning policy

In February 2010, ADHC issued draft *Lifestyle Planning* policy and practice guidelines for comment, following consultation with ADHC frontline staff and management. The policy marks a shift to person-centred planning and support, with guidance for staff on supporting people with disabilities to 'plan the life they want to lead' through the development of lifestyle plans. Of note, one of the guiding principles of the policy is that the person with disability '*is central to the planning process, representing a shift in power and control over the outcomes, towards the person.*'

In our feedback to ADHC on the draft policy and practice guidelines, we welcomed the emphasis on person-centred planning, but commented that:

- there needs to be greater emphasis in the policy on the involvement of the person with disability, and clear guidance for staff on how to facilitate and foster decision-making and choice;
- the policy needs to be accessible to people with disabilities and all staff, regardless of their level of education;
- there needs to be much greater guidance for staff in how to undertake person-centred planning, including how to identify what is important for and to the person.

The move to person-centred planning provides a useful and timely opportunity for ADHC to mark a significant shift in the way services and supports for people with disabilities are planned and delivered. However, the final policy will need to be supported by intensive staff training and comprehensive resources. ADHC has indicated that it intends to support the roll out of the policy with a substantial learning and development commitment.

We understand that ADHC intends to roll out the final policy to staff in 2010, for implementation in early 2011.

Implications for people with disabilities in ADHC's residential centres

A shift to true person-centred planning and support has the capacity to address a number of the issues we have identified. However, the introduction of a new policy will not, in and of itself, deliver the necessary change. Without fundamental reform of the way services are planned and delivered, there is a real danger that, in practice, person-centred planning will continue to be the existing individual planning process but under a different name.

As it stands, the existing model of service delivery in ADHC's residential centres is in conflict with person-centred planning principles. Overall, there is a need to change from support being driven by the service system, to being driven by each person's needs, goals and preferred lifestyle. In making this observation, we also note that it is not clear to us how this can be done in a congregate environment, and with the existing resource constraints.

In responding to the issues identified in the draft of our *Review of individual planning* report, ADHC referred to the changes in service provision that will occur with the closure and redevelopment of its residential centres. ADHC told us that the expected changes include the development of accommodation models that incorporate individual bedrooms, maximise residents' independence and choice, and enhance opportunities for involvement in local communities and activities.

However, plans to close or redevelop ADHC residential centres currently only apply to Peat Island, Lachlan, and Riverside centres. This means that there are no plans that have been made public regarding the devolution of the remaining six centres, including the two largest ADHC residences of Stockton and Rydalmere.

NSW Ombudsman

Level 24, 580 George Street

Sydney NSW 2000

General inquiries: 02 9286 1000

Facsimile: 02 9283 2911

Toll free (outside Sydney metro): 1800 451 524

Tel. typewriter (TTY): 02 9264 8050

Web: www.ombo.nsw.gov.au



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