Office of the Public Advocate

South Australian Council on Intellectual Disability Annual General Meeting 2008
Invited Presentation by the Public Advocate on the topic of Community Visitors Schemes

The Public Advocate is an independent official accountable to the Parliament of South Australia

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1 INTRODUCTION

There is real concern from many quarters that South Australia needs independent trained visitors to visit community and institutional accommodation for people who have an intellectual disability. Recently, we've seen significant discussion about the role of community visitors from a number of quarters within the disability community, partly triggered by a review this year of the legislation governing the Health and Community Complaints Commissioner in this state.

While there is no immediate plan to establish a Community Visitors Scheme in South Australia, this discussion considers what outcomes community visitors can achieve, and their role in a range of strategies to safeguard vulnerable people in community or institutional accommodation. Community visitors offer a key safeguard, but they are not the total answer. Other components of a system of safeguards need to be in place alongside them. This include periodic regulatory and accreditation inspections to look at the professional and technical aspects of care, and the development of mandatory reporting regimes for when people in facilities are the victims of sexual assault or serious physical assault.

The discussion is in the context of the role of Public Advocate. A Community Visitors scheme might potentially operate with a number of different statutory authorities, but collaboration in running it would be a key factor, as well as the sharing of "intelligence" the Visitors collect about what is really happening on the ground. Information from Community Visitors can significantly enhance the systems advocacy role of the Public Advocate's office.

GENERAL FUNCTIONS OF THE PUBLIC ADVOCATE

The general functions of the Public Advocate are described within Division 3 of The Guardianship and Administration Act 1993. The functions are:

1. The functions of the Public Advocate are—

a) to keep under review, within both the public and the private sector, all programs designed to meet the needs of mentally incapacitated persons;

b) to identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the Minister the development of programs for meeting those needs or the improvement of existing programs;

c) to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;

d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;

e) to give support to and promote the interests of carers of mentally incapacitated persons;

f) to give advice on the powers that may be exercised under this Act in relation to mentally incapacitated persons, on the operation of this Act generally and on appropriate alternatives to taking action under this Act;

g) to monitor the administration of this Act and, if he or she thinks fit, make recommendations to the Minister for legislative change; and

h) to perform such other functions as are assigned to the Public Advocate by or under this Act or any other Act.

This independent position advocates for the needs of mentally incapacitated people. The definition of mental incapacity from The Guardianship and Administration Act is outlined below:

mental incapacity means the inability of a person to look after his or her own health, safety or welfare or to manage his or her own affairs, as a result of—

a) any damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration, of the brain or mind; or

b) any physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever.

2 BACKGROUND TO COMMUNITY VISITORS SCHEMES

Community visitors schemes currently operate in other states of Australia, and empower members of the community to visit institutions and community residences to identify abuse or neglect, advocate for the best possible assessment and treatment, assess the standard of facilities and their care for people, and ensure that there are maximum opportunities for recreation, occupation, education, training and rehabilitation.

Community visitors bring community standards into the institution. They are an addition to accreditation or regulatory inspections performed by professionals (where such regimes exist). In centres with longer-term patients, consumers are able to develop a trust in their community visitor and gain the confidence to raise issues, knowing that if there are any problems after the issue has been raised the community visitor will be back in two to four weeks for a follow up visit.

In Victoria, the mission of the statewide Community Visitors Program is to promote and protect the rights of people with disabilities and reduce exploitation, abuse and neglect (Office of the Public Advocate, 2007). Visitors are appointed by the Governor in Council. The community visitors report directly to Parliament, and their influence matters. Their goals include looking at opportunities for people to participate in recreation, occupation, education, training and rehabilitation, rather than just receiving minimal care.

Community Visitors are usually there more frequently than regulatory and accreditation inspectors. Regulatory inspections by technical experts can audit buildings, delivery of programs and compliance with policy and standards. However, regular intervening visits by community visitors can complement this, as visitors acquire a depth of information because of the relationships they establish with residents. Residents know that the visitor will return, giving them confidence.

3 WHAT DOES A COMMUNITY VISITOR ASSESS?

Community visitors bring community values and standards into care settings. They regularly visit a range of settings where people live or are cared for: small group homes in the community, institutional settings, supported residential facilities, and mental health facilities. They meet people, inspect facilities, ensure that individuals' needs are met, and check that problems raised on the last visit have been corrected. They check that residents have not suffered because they have raised a problem; that retribution after a matter has been raised has not occurred.

Visitors are advocates and receivers of complaints. Because they visit regularly, relationships develop with the people they meet, who can be confident that if they raise an issue with a visitor, that the visitor will be back to follow it up. This also protects against potential victimisation of people who raise issues, because of their ongoing connection.

Because community visitors work comprehensively across all residential services they can identify systemic issues, and collect intelligence to tackle problems. This intelligence is different to evidence required for a complaint. While complaints (requiring names and evidence) may be lodged with community visitors, oftentimes people are not willing to come forward with names and dates. In these cases, community visitors can use the intelligence to asks managers to fix systemic problems

Community visitors are not technical regulatory inspectors or quality controllers. However, they can value add in many ways, including:

Dignity and rights of the consumer

Community visitors assess a large range of serious issues, including evidence of respect (or lack of it), appropriate treatment, privacy, and consumers' access to information about their care. They can respond to claims of significant abuse or neglect. More frequently, they can deal with day-to-day matters that may not be serious in themselves, but still affect people greatly over time. How often do you hear reports of certain staff members not responding, not taking consumer requests seriously, not being attentive, or even getting into arguments with their clients? The community visitor can tackle these issues and talk with managers about the behaviours. They can do this in a manner that other groups cannot.

Support for staff

We cannot always rely on other staff to raise issues of colleagues performance. With more entrenched problems other staff may feel intimidated themselves. So many times in a home or institutional setting we hear about great staff present who haven't been able to fix the problems on their clients' behalf.

Dignity and rights of families

It is also hard for carers and family to address these issues. Visits of family should be about enjoying company. Clearly, though, in some situations the family visit ends up being a quality and safety check, because they cannot be sure things are being done. Families should not have to do this week after week, month after month. It is difficult for families to 'steel themselves' again and again to raise issues with staff, or to take matters to the manager. What should be happy visits often become another source of worry. While there will always be some situations where families raise issues that others don't, it should not be routinely necessary. What's more, there are many people receiving care who do not have families to visit, or who have families who feel apprehensive about raising problems.

Visitors can take on much of this. Because it is their role, if they come back and find that the person they are visiting is not getting what has been asked for, they will escalate the issue. It is their job to do so. While it may be quite stressful for each carer or consumer to continually address an issue, it is part of the community visitor's role to take matters to managers, service directors, back to the Office of the Public Advocate, to Ministers, local MPs, to Parliament in the annual report, and to the media.

With Community Visitors Schemes in existence for so long in other states, it may be fair to assume that they might have now done themselves out of a job. However, there always seems to be new problems emerging, or old problems emerging in new ways in new community settings. Ongoing transparency is needed.

Providing consumers with choice

The ability for a consumer to have choice and make decisions is vital. This can be any decision such as work, recreation, going out, what a person does at home, choice of food to eat - all the basics of a good life.

Community visitors can tackle the common problems in group homes. A person will have their own choices about what they want to do, where they want to go, what their interests are. Feedback given to the Office of the Public Advocate about group homes suggests that

if you are quiet and don't get your message through, you may end up doing what your fellow resident wants to do, rather than what you want to do. If there is limited transport, you could be bundled off where they want to go, rather than getting to do what you want to.

There is also the issue of choice in accommodation and services. Whether you want to live alone, with others and where you want to live are all valid choices, and ones that community visitors schemes support.

Some people see choice as part of the solution to quality problems – even to the extent that it is suggested that if people have genuine choice, they will avoid the poorer providers, and a community visitors scheme will not be necessary. However, choice alone will not guarantee safe care and quality care, and that other safeguards – in this case community visitors – are needed. In fact, as we move to giving more choice, the visitors can check to help ensure that people are getting to fully use it.

The issue of choice is fundamental, but there also must be some additional oversight, accountability and monitoring. This particular applies for people who may not easily communicate their wishes, and who fear retribution if they make a complaint about the services they fundamentally depend on each day.

Regulations and mandatory reporting

Regulatory visits are another part of the equation. These include inspections to ensure that necessary building standards, service standards and training are maintained. Inspections can assess technical detail of care provided. These reviews alone, along with accreditation, are not sufficient by themselves. In states where there are regulatory inspections and well-established complaints mechanisms, community visitors still have a role. Community visitors can bring the community standards of citizenship to bear by looking at care providers. We need both, and each type of visitor – the community visitor or the technical inspector - needs to be clear about their role and the value they bring.

Another complementary strategy is the mandatory reporting of assault. Such requirements exist for minors, and they also exist in commonwealth funded aged care facilities. According to a key study from the early 1990s cited by a recent Australian Institute of Families study paper, people with an intellectual disability are at greater risk of assault, and are twice as likely to be a victim of personal crime compared to the general population, and ten times more likely to be the victim of a sexual assault.

Mandatory notification not only has value in stopping ongoing abuse, it also sends a powerful message about what is not acceptable. The topic for mandatory notification has been subject to much academic debate. But even those who see mandatory notification as paternalistic would acknowledge that some sort of system is required so that people who cannot communicate - either because of their disability, because of their fear or because of their institutional reliance on support workers - can be protected against harmful and predatory behaviour.

Other areas addressed by community visitors

While performing their duties, community visitors can also look at:

- Progress with individual plans. Is the plan real? Does it include the consumer's goals? Are resources being allocated to work towards the plan?
- Are people engaged? Can they take risks? Are they safe, while not being overprotected? Does the person know how to complain? Do they have the opportunity to be involved in community groups or to go shopping? Or are they left to sit either at home or at the shops, feeling unengaged?
- Is money being spent as it should be?
- Is care as least restrictive as possible?
- How is incompatibility with fellow residents addressed? Mixing the wrong group together may make some people's lives very unhappy. If these incompatibilities are recognised, is action taken to resolve it?
- Does the resident get necessary health care? In Australia, adults with intellectual disabilities often have untreated medical illnesses that are not picked up, and who do not get the routine preventative care that they should receive.
- Do they see the dentist? Dental care is the great marker of inequality in this country. There are implications for total health, not to mention the misery of not being able to eat properly, experiencing dental pain and the stigma or poorly fitting dentures.
- Is the person receiving adequate mental health support? Co-morbidity is common, but accurate diagnosis is an issue.
- If the consumer is an older person, can he or she age in the place they currently reside?

A community visitors scheme is only part of a suite of actions that can help prevent abuse and neglect, and ensure that people have the opportunities they need to pursue life the way they want to.

4 COMMUNITY VISITORS AND SYSTEM ADVOCACY

The function of a community visitors scheme is relevant to the role of the Public Advocate, as it is pertinent to key functions of reviewing services and considering unmet need. This is not to say that a Community Visitors Scheme must reside with the Public Advocate - such a scheme could be successfully operated by a number of different agencies. Regardless of the agency overseeing such as scheme, it would be necessary for close collaboration between agencies responsible for advocacy, complaints and system oversight.

There are direct benefits of the community visitors working closely with the OPA, as already noted, the systems advocacy function of the Public Advocate becomes extremely well informed by the 'intelligence' collected by the community visitors.

The Victorian Public Advocate has 500 visitors in the system identifying problems, advocating, negotiating and receiving complaints. In South Australia, this would correspond to about 150 visitors, based on our population size working across all services (disability accommodation, supported residential facilities, and mental health services). For disability services there would be about 1,000 visits per year needed in this state.

5 CONCLUSION

It is important to consider the question of value for money, as there is some cost involved in establishing a community visitors scheme. For example, the volunteer model still requires training, co-ordination and payment of honorariums to each visitor to cover costs. This would be money that might otherwise be used to pay for extra workers or equipment.

However, the Public Advocate believes that community visitor schemes can create new investments. In other states of Australia, community visitors have been able to point out deficiencies in services and advocate for new services and facilities, which has resulted in significant new service investments.

Finally, leadership is critical in setting cultures. Many of the issues that are raised relate to culture, or to training and education of staff. Most service leaders value the accountability and transparency of a community visitor scheme that assists them their role. Leaders want visitors. Visitors need effective leaders to address what they raise.

No one strategy is a solution, but community visitors can complement a range of approaches – this includes regulatory inspections, systems to ensure mandatory reporting of serious matters, as well as community visitors.

John Brayley
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