ANGLICARE
TASMANIA

Your care, your say:
consumer and community engagement

Response to consultation paper

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1. Introduction

Anglicare Tasmania welcomes the opportunity to contribute to the consultation on consumer and community engagement.

The views expressed in this submission are based on two aspects of the work of the Social Action and Research Centre (SARC), Anglicare's research and policy division. The first is a current research project which has focussed on consumer engagement mechanisms in the mental health sector (Hinton in press). Consumers of mental health services have, for the past two decades, been campaigning to ensure that the 'lived experience' of mental illness becomes an accepted part of decision making and intrinsic to reform in the mental health sector. This means that there has been some profound thinking about how best to actively engage with the views of mental health consumers so that they can influence policy, planning and service delivery and improve the quality of services and outcomes for consumers. The lessons from these debates can usefully inform the development of a consumer and community engagement strategy in Tasmania.

The second is SARC's expertise in the housing area and its long history of contributing towards the development of state housing policy. This has included coordinating, together with Shelter Tasmania and the Tasmanian Council of Social Service, a community sector advocacy campaign on the housing crisis culminating in an advocacy day at Parliament House in 2007. Anglicare was also involved in the working groups that supported the development of the State Government's Affordable Housing Strategy and was a driving force in the establishment of the Affordable Housing Crisis Coalition, a coalition of housing service providers, community and industry peak bodies and unions advocating for a range of detailed policy and funding measures in response to the housing crisis. Throughout the course of this work SARC has been able to reflect on tenant participation mechanisms in Tasmania.

This submission agrees with many of the points raised in the *Your care, your say* consultation paper (DHHS 2009). It takes it as a given that consumer and community engagement is important and that it is key in improving the quality of services and the care, treatment, support and policy outcomes for consumers. It is also a democratic right and vital for ensuring accountability. This submission also supports the basic principles and key implementation issues as outlined in the consultation document. In particular Anglicare agrees that getting it right will take time, that participation activities need to be meaningful and a part of everyday work and that two of the key issues are time and resourcing. Given the number and range of consultations with Department of Health and Human Services (DHHS) consumers it is vital to have a strong mechanism for reporting how any input has influenced decisions in order to avoid consultation fatigue and cynicism.

The main part of this submission addresses the question of what needs to be in place for engagement to work effectively using the mental health and housing sectors as examples.

2. About Anglicare

Anglicare Tasmania is a non-government organisation that has been working for the Tasmanian community for the past 25 years. Since its establishment it has grown into a state-wide organisation responding to issues faced by Tasmanians such as financial crisis, homelessness, unemployment, the adverse health, social and economic consequences of alcohol and other drug use, and the challenges faced by people with physical and intellectual disabilities or mental health problems.

Part of Anglicare's mission is to speak out against poverty and injustice and to offer alternatives to decision-makers to help build a more just society. Anglicare practices this advocacy through its Social Action and Research Centre, which was established in 1995 to work with low income earners to identify the issues that affect them and then carry these concerns to Government. Over the past 14 years SARC has produced a series of major research reports on these issues including access to health care, unemployment, financial crisis, mental illness and disability.

The issue of consumer engagement is a key priority for Anglicare and it would like to ensure a consistent approach to involving consumers across the range of its programs and services. Consumer engagement and advocacy is now also a priority area for the SARC team and identified as such in SARC's three-year strategic plan.

3. Mental health consumer activities: research findings

SARC has recently completed research which has examined the achievements and struggles of the mental health consumer movement across Australia in order to inform the development of mental health consumer activities in Tasmania (Hinton in press). Using information collated from a literature review and one-to-one interviews with over 70 consumers and other stakeholders it maps consumer initiatives and activities nationally and overseas, describes the key themes and issues mental health consumers face and presents some options for Tasmania.

At one end of the spectrum there are participation activities controlled by non-consumer stakeholders where opportunities are made available for consumers to become involved in areas ranging from individual treatment plans through to decisions about policy and services. At the other end of the spectrum are consumer driven and controlled advocacy services offering leadership by and with people who share the experience of what it means to be a consumer, and overseeing the development of the mental health consumer community. SARC research has focused on this end of the spectrum.

The key findings of the research are:

- **Nationally and internationally the mental health consumer movement can claim a number of successes.** Its two key aims – to transform mental health provision into a recovery-orientated service and to ensure consumer participation is an accepted and routine part of service delivery and evaluation, policy and planning – are now accepted goals for those making decisions about mental health services. In Australia a recovery focus has become a cornerstone of mental health policy and mental health services are required to promote the participation of consumers at all levels. Today the mental health consumer movement is established, accepted and seen as being a good thing.

- **Across Australia there is a complex jigsaw of consumer activities and participation mechanisms.** These range from small consumer support and self-help groups and involvement in decisions about treatment through to a paid consumer workforce, consumer advocacy organisations and consumer-run services. The report identifies two major strategies: working within the system to promote cultural change and working outside the system in independent consumer organisations to advocate for systemic change and to role-model alternative services. Each jurisdiction is different but most have witnessed a burgeoning of consumer initiatives on the ground accompanied by a push to develop state-wide and national consumer run peaks and a consumer workforce.

- **For many consumers and other commentators the consumer movement has not reached its full potential.** Participation and advocacy activities are patchy, funding and resourcing often inadequate and consumer run organisations and services struggle to survive. In many places there has been a failure to translate support for consumer initiatives and participation mechanisms into the financial resources and the capacity building required to make them work effectively. The major obstacles are:
  - professional attitudes and resistance and a lack of awareness of the value of the consumer perspective;
  - a gap between the requirement for participation at a political level and the lack of mandates about how processes or mechanisms should be facilitated;
  - a diffuse sector which encompasses public and private services, GPs working autonomously and diverse community service organisations (CSOs);
  - consumer confidence and the risks of personal exposure;
  - tokenism caused by little infrastructure to facilitate involvement; and
  - inadequate resourcing which sees consumer participation as a money neutral priority.

- Key issues for the mental health consumer movement identified in the literature review are about **how best to promote a recovery agenda so that it becomes a reality for mental health consumers and how to progress the cultural change necessary to remove the barriers to effective participation in clinical services**. There are also issues about the most effective way to develop a consumer workforce, the pros and cons of working with carers, the meaning of consumer leadership and representation and the establishment and sustainability of consumer-run organisations.

- **In Tasmania, and despite active and influential consumers, there have been low levels of consumer activity and the state lags behind other jurisdictions.** The main participation mechanisms have been
  - TASCAG – an independent ministerial advisory committee on mental health;
  - a consumer-run consultancy project which began to develop a consumer workforce in the south;
  - the Tasmanian Mental Health Consumer Network which, for the past three years, has performed an important role in advocating for system improvement and improved community attitudes and worked to strengthen the mental health consumer community; and
  - a growth in small consumer support and self-help groups across the state.

  However, Tasmania's small and dispersed population and a lack of financial and other resources have mitigated against state wide consumer activity and involvement and raised concerns about the sustainability of consumer-run initiatives.

The research clearly demonstrates that the difficulties faced by Tasmanian mental health consumers in getting involved and by mental health service providers in facilitating involvement are shared by other jurisdictions. It also demonstrates that although there is no 'road map' and no easy solution there are valuable lessons to be learnt from experiences in elsewhere in Australia and internationally.

4. Tenant participation in Tasmania

Research indicates that, as with levels of mental health consumer involvement, Tasmanian tenants have less capacity than in a number of other jurisdictions to get involved. The 2007 National Social Housing Survey (AIHW 2007) shows that although levels of actual involvement match the national average, more than half (54%) of Tasmanian respondents did not know anything about tenant participation groups compared to 42% nationally and that only 11% said that they knew of groups, although they had not been involved, compared to 25% nationally. In addition 15% said there were no groups in their area compared to 12% nationally. Anecdotally housing providers have commented that few tenant groups exist. Those that do exist tend to be focussed around individual unit complexes and concentrate on the issues specific to that complex, for example anti-social behaviour. There are also reported difficulties in sustaining any group on a long-term basis.

Research exploring housing regeneration programs and exit strategies (Jacobs et al. 2007) included a Tasmanian case study of a regeneration project that had formally ended with a community-based agency established to maintain the achievements of the program. The research found that the good work of this organisation was due not necessarily to planning but to the commitment and motivation of an individual. The death of this person left a considerable gap. The research also found that there was a need for capacity building and training projects with residents prior to exit to ensure that the required infrastructure existed, as well as a need for business planning, long term recurrent funding, a dedicated community based staff and successor organisations with community governance arrangements.

A study of resident participation in urban renewal programs in Australia (Wood 2003) found that:

- promoting resident participation in urban renewal programs required a community development approach;
- ‘community participation’ as a concept was not clearly defined in the minds of housing providers;
- participation structures were important. Some states used forums involving local agencies, volunteer groups and local resident representatives which met regularly to provide input. However few residents took an active part in them and only two had a mechanism allowing residents to have direct input (through sitting on project steering committees);
- constant communication was important to maintain involvement and the main method used was newsletters; and
- barriers to involvement were numerous. They included the life experiences of residents, which had lead to low self-esteem, stigma, apathy and dependence, as well as a cynicism and scepticism resulting from earlier failed programs or programs with inadequate consultation. They also included overly formal consultative or participatory processes (e.g. meetings which used exclusive language), inappropriate meeting times and venues and the failure to provide childcare for parents. Many residents were unaware consultative forums existed or did not feel that participants represented their views, while community representatives themselves felt they were being dominated, ignored or manipulated by renewal professionals, that they were constrained or limited in their role and that all the work was being left to them even though they felt they lacked ability to do it. In addition there were problems with the exclusion of key cultural groups, especially those from non-English speaking backgrounds, despite the extensive use of interpreters. There were concerns among professionals that those residents who did participate were not sufficiently representative. High levels of conflict at some of the community meetings had also distressed some residents and put them off further participation.

The study summarises the implications for good practice in this area, which include the following:

- residents require the skills to participate but renewal professionals do not often see supporting residents to develop skills as their role;

- it is critical to begin with the views of local people, and start the process before plans have been drawn up so that the development of policy starts with consultation rather than ending with it. This is achieved by strengthening and resourcing existing groups and promoting the inclusion of those who are excluded. It also requires targeting resources initially at the issues which are of most importance to residents in order to build confidence in the process and combat disillusionment;
- participation structures need to be open and give people a choice over their level of involvement. They need to maximise accessibility (e.g. through providing childcare or interpreters or ensuring meeting times are appropriate), to broaden participation beyond existing community activists, maintain ongoing communication and publicity and give residents genuine power in the process; and
- people must have proof that they are getting results – either through witnessing action being taken in response to their views or being provided with explanations as to why this is not possible. Monitoring and evaluation can be used to confirm to residents that they have influenced the process.

Overall the study concludes that community participation is not an easy or cheap option. It can take years and requires skilled and experienced workers to facilitate involvement. It requires accessible local facilities and training and community development support for community groups, with the ultimate aim of employing local people in community development roles. This all requires adequate resourcing.

One of the biggest challenges for establishing a permanent infrastructure in Tasmania to support public housing consumer engagement is the difficulty in maintaining people's interest and involvement when there is no particular current project or issue with which participants can engage. However, as with mental health consumer activity, when appropriately supported, public housing tenants' engagement in their housing and communities does not have to be confined to providing input to government. As one public tenant advocacy group in Victoria has pointed out, prior to de-funding during the 1990s, public housing tenant groups were responsible for many effective community programs on public housing estates which engaged tenants in their communities and improved their quality of life, including playgrounds, security, child care, food cooperatives and social programs, (Housing for the Aged Action Group 2001).

5. Lessons for consumer engagement strategies

Experiences in both the mental health and public housing tenant participation areas demonstrate the necessity to build capacity (or engagement enablers) and to create an infrastructure and environment which will allow engagement mechanisms to be established and to flourish. The key tasks are to change the culture and attitudes of both providers and consumers to enable participation, provide a fertile regulatory environment to encourage and promote involvement activity and to provide adequate resourcing to facilitate involvement activities. These are the basic building blocks of consumer participation.

The research shows that **changing the culture and attitudes** requires:

- **training for providers at all levels** to respect the consumer, understand what consumer engagement means, be aware of its benefits and know how to involve consumers in decision making at both an individual treatment level and at a systemic level. In the housing field this would help to overcome common perceptions among providers that strategic issues are too complex for consumers to understand, that engagement would only cause consumers worry and anxiety and that consumers only care about their own day-to-day life and are therefore unable to make any meaningful strategic input. Anglicare research shows that, certainly in the mental health field, one of the most effective approaches is involving consumers as trainers and educators. This has positive results and can reverse the low expectations providers hold about consumers' ability to recover and to participate. Consumers need to be involved in the on-going training of the health and human services workforce and in the tertiary education of health and human services professionals;
- **training for consumers** to build the skills which will enable them to effectively participate. This involves building self esteem, making people aware of their rights so they are better able to negotiate services and lifting their expectations so they can demand improved services. Improved confidence can also assist in supporting consumers to overcome barriers to participation;
- **developing a paid consumer workforce** to integrate a consumer perspective into services and build a consumer leadership to facilitate cultural change and promote positive consumer role models. This is a well developed approach in the mental health sector but not in other sectors. It might include employing consumer representatives, consumer advisors and consumer educators. For tenants it might include employing local residents in community development roles;
- **an environment which nurtures the development of consumer groups and local networks**;
- **involvement mechanisms at every level** which are well publicised and include practical support for consumers to participate; for example remuneration, training, mentoring, support, assistance with transport, child care and interpreting, and welcoming environments; and
- **a comprehensive communications strategy** which can demonstrate a commitment to openness and transparency by government. This should provide full information to health and human services consumers about what they can expect in terms of care, treatment, services and rights as well as information and education about complex reform issues to enable them to participate.

Providing a **fertile regulatory environment** requires:

- **health and human service position descriptions which include participation components**;
- **legislation** to bridge the gap between the requirement for participation and room for local interpretation. There is a need to make legislation more prescriptive about consumer engagement across diverse sectors. The inclusion of consumer participation requirements in legislation can provide additional incentives for implementing effective engagement strategies, particularly when consumers are 'hard-to-reach' and engagement is difficult, and a legislative requirement can also be used to drive funding decisions, ensuring that resources are available to support engagement activities;

- **policies to ensure it is safe for consumers to get involved**;
- **independent advocacy** in every area;
- **a commitment to working with hard-to-reach groups** who may require different approaches; for example people who are homeless or ex-prisoners; and
- **monitoring and evaluation mechanisms** to audit the progress of consumer engagement activities and how to improve them and to support the provision of information back to consumers and the community about how their input has been utilised by the Department.

Any capacity building cannot occur without **adequate resourcing**.

Overall experience shows the need for a commitment to consultation and engagement to be held from the Minister on down to staff on the ground. This must be accompanied by recognition that consumers are significantly affected by issues like a change of service provider, changes to service delivery structures and the contracting out of services and need to be supported to have input into these areas as well as in areas relating to their individual care and use of services.

6. Establishing a peak body

The consultation paper suggests that one way forward may be to establish a peak body that reflects broad consumer and community interests across the health and human services sector. A peak body could potentially provide one mechanism for undertaking some of the capacity building required. Examples from the SARC research on mental health consumer activity include:

- **the Health Consumer Alliance in South Australia** was established in 2002 as the peak body for health consumers. It aims to provide an independent health consumer voice, play an active role in the development of policy affecting health consumers, promote public discussion, provide education and support for consumers and community groups to achieve health system change and support disadvantaged groups. It assists consumers to develop skills in advocacy and representation and lobbying and undertakes community information projects to raise awareness. It offers consultation and information about preferred strategies and frameworks and produces factsheets about participation.

- **the Health Consumers Council in Western Australia** was established in 1993 as an independent patient group and it comments publically on all health matters. It aims to ensure health consumers contribute to the development of health policy, research and service delivery. Among other things it provides training, consumer representatives, information on rights and guidelines for consumer payments.

- **the Health Issues Centre in Victoria** is an independent body which aims to promote equity and consumer perspectives in the health system. The Centre undertakes focused research, and supports consumer participation, policy analysis and advocacy from a consumer perspective. It offers consultancy services on participation and has undertaken projects such as the development of a comprehensive suite of performance indicators.

A peak body for health and human services consumers in Tasmania could provide a range of advocacy and information services for consumers as well as a focal point for training initiatives and leadership building. However, current proposals for such a body suggest that any consumer peak would represent the interests of consumers across health and human services. This is a very broad remit which includes a wide diversity of interests. Representing such a breadth of concerns would clearly be difficult and would require strong linkages with a membership of effective consumer organisations and networks and a commitment to proactive engagement across all groups of consumers. It requires appropriately qualified staff, the capacity to engage and represent consumers across the state, a marketing budget to increase public awareness of its services and the capacity to become a focal point for training initiatives and building consumer groups and networks. It also requires significant resources to be able to effectively consult with all of its membership, some of which would not be in a position to use or access lower-cost methods of communication such as email.

It is also important to recognise that such a peak body will take time to become established and build up its reputation and influence. In its initial stages it may be helpful for the organisation to receive support or mentoring from a successful and more established organisation interstate, although it is important that this process does not undermine the Tasmanian peak's accountability to its own community or its relationships with its members and networks.

7. Recommendations

Anglicare would like to see investment in building the capacity of consumers to effectively participate through establishing the necessary infrastructure including consumer-run organisations and networks and a consumer workforce. Anglicare recommends:

- That the Department of Health and Human Services make a senior level appointment in each business unit to oversee and take responsibility for the implementation of a consumer engagement agenda and to build the capacity of consumers to participate and of providers to facilitate that participation.

- That the Department of Health and Human Services provide opportunities for the training of consumers in order to build their capacity to participate.

- That a requirement for consumer engagement, including the building of a consumer workforce, is built into contractual requirements for CSOs delivering government-funded services and that the existence of consumer engagement mechanisms are a key quality indicator for CSOs.

- That the Department of Health and Human Services make the consumer perspective intrinsic to all aspects of the education and training of the health and human services workforce by using consumer educators.

- That the Department of Health and Human Services ensure that mechanisms are available to develop and nurture consumer groups in all health and human service sectors across the state. These mechanisms may include policies and procedures to ensure practical support and assistance is available to consumers wishing to participate, a comprehensive and ongoing communications strategy, legislative reform to require consumer engagement, including of the 'hard-to-reach', across all health and human services and an effective monitoring and evaluation strategy.

- That the Department of Health and Human Services strengthen consumer engagement with Tasmania's health and human service system by establishing a well-resourced peak body to represent consumers and the community, to support engagement activities and to strengthen consumer networks and organisations.

8. References

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