

# **Your Care, Your Say**

## **Consumer and Community Engagement (CCE) Consultation Paper**

### **Submission from Advocacy Tasmania Inc**

**May 2009**

#### **Introduction**

Advocacy Tasmania applauds Health and Human Services for initiating this consultation. It remains the Consultation Paper leaves a great deal of work to be done. It is descriptive, rather than formative. It selectively describes practice elsewhere, rather than analyses and develops Tasmania-specific approaches, despite the request (Q4, p17) to comment thereon.

A further concern for Advocacy Tasmania is that the Paper's language, definitions, categories, and expectations appear prescriptive. Perhaps unconsciously, it is a 'top down' approach and language. The Paper *de facto* captures CCE within a narrow frame of reference. Our internal discussions – Board, staff – reflected a concern that the Paper focused on 'how we (services) can engage you (other) so we (services) can do for you (other)', rather than an iterative and level-playing-field understanding of 'what we can do together'.<sup>1</sup> There is a marked sense in which the parameters of the debate appear to have been set by the Department, with consumers expected to contribute within defined processes and bureaucratic boundaries.

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<sup>1</sup> See Appendices. Appendix 2 is the product of a consultation on the Paper with a group of our clients such as we undertake regularly with respect to various matters.

A related concern is that the Paper flags engagement across a very wide ambit of services and functions. This may easily oversimplify engagement unworkably and risk tokenism. Mainstream health service consumers do not generally experience the same barriers or limitations as the consumers typically represented by Advocacy Tasmania. A further concern is that the Paper ignores existing engagement mechanisms, which we suggest require protection and strengthening. We return to these issues, below.

### **Consumer and Community Engagement – the contemporary environment**

Internationally, many jurisdictions are in the process of developing, implementing, or have implemented health consumer engagement strategic plans. A great deal of work elsewhere informs these processes. It remains the Paper provides little guidance as to how or why the models discussed may fit within the unique Tasmanian environment. This is particularly important given that the Government appears to have made the decision to impose upon a health care framework both a health care and a human services consumer engagement function. To the best of our knowledge, this is not an approach which has been adopted elsewhere, and its feasibility is thus unproven – there is no evidential base.

From our reading of the Paper, the proposed consumer engagement is intended to differ from existing community consultation processes. As a partnership relationship, it is to be founded on the respect to be given to the roles and values of each party, a commitment by government to openness and accountability, and on the quality of information which flows both ways. As it stands, the Paper does not address how this process will proceed, what will happen to consumer input, whether a discussion paper will be followed by a Draft Plan, the timelines for the process, whether there will be regional public forums, or whether the responses to the Consultation Paper will be all that is required from consumers before the Department releases a Consumer Engagement Plan.

We are acutely aware that present consultation processes are viewed with profound scepticism by consumers and many providers.<sup>2</sup> It is fundamentally important for the Department to demonstrate to consumers and other stakeholders:

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<sup>2</sup> See Appendices

- why a Tasmanian Consumer Engagement Plan is important;
- why consumers should participate in the development of the Plan, and
- why a Health and Human Services framework should be adopted.

If Tasmanian consumers are to have a real say, they require Government commitment to properly fund, resource and support their involvement in the engagement process. There is wide disparity between the needs and priorities of those who have an intellectual disability, an acquired brain injury, dementia, a mental illness, who are young people in the youth justice system, victims of elder abuse, or are forcibly detained and treated within the forensic health system. This disparity is difficult to address or engage uniformly from an operational perspective, despite some overlap of broad principles and practice. These difficulties are acknowledged but not addressed by the Consultation Paper.

## **1. Is consumer and community engagement important?**

Advocacy Tasmania regards the development of partnership approaches to health and well-being as essential. These will include a range of mechanisms from the individual to community-based levels. Our position reflects several understandings:

- first, it is internationally recognised, beyond question, that consumers provide understandings and insights into the operations of services that no others can provide. A service delivery system is administratively negligent insofar as it ignores this information;
- secondly, these processes are now recognised as fundamental requirements of a rights-based understanding of individual and community health and well-being. They are increasingly required by law, where modern human rights provisions are enacted.

From an operational perspective, as the Consultation Paper recognises, engagement options encompass a wide span from information to control. There is no 'one size fits all' solution. As above, the Paper is deficient insofar as it provides no operational guidance

as to any possible or proposed Tasmanian approach(es). The operational questions not addressed are:

- what mix of approaches is important In Tasmania
- for which groups of consumers, and
- with what specific objectives of engagement, with respect to these diverse groups?

### **Transparency and accountability**

Transparency and accountability are given as key objectives with respect to engagement. In our view, questions remain whether consumer engagement mechanisms ‘ensure accountability’ (p 6), and if so, which mechanisms, and in what way(s)? Transparency, accountability and consultation are relatively recent principles in government policy development and decision-making. They form part of an ambiguous and uncertain policy environment. While there are welcome recent moves toward transparency and accountability, including the capacity to access and learn from decision and delivery processes – the present reform of FOI laws is a good example – it remains there are counter-veiling pressures and trends. A recent audit of Australian legislation found three hundred and fifty five (355) state and federal laws containing secrecy provisions.<sup>3</sup> An excellent example of such inappropriate and regressive legislation is S4 of the *Tasmanian Health Act 1997*.<sup>4</sup> These conflicting trends are mirrored internationally, and the questions at issue are far from resolved. It is naïve to state, and more importantly believe, that consumer engagement in some way automatically ensures accountability. What ensures accountability is government leadership in guaranteeing processes that are transparent and accountable for (and to) consumers, and enshrining and enforcing these guarantees in legislation, regulations and policies.

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<sup>3</sup> Laurie Oakes, Hobart *Mercury*, 2 May 2009

<sup>4</sup> S4 stringently precludes access to persons and information concerning serious adverse events by review bodies, including the Health Complaints Commissioner, Mental Health Tribunal and Guardianship and Administration Board.

## **Existing engagement and review mechanisms**

In these terms, the Consultation Paper is further deficient in that it has no regard to existing engagement mechanisms which are powerful rights-protectors. Internationally various bodies/mechanisms have long offered consumers direct engagement with services via intermediaries with the skills, capacities and responsibilities to analyse and reflect upon services. The approach taken fails to recognise that Tasmania, as with most developed Western jurisdictions, already possesses a range of mechanisms which enable and reflect significant consumer and community engagement. These include a wide range of oversight and review mechanisms, for example the Health Complaints Commissioner (whole of Health), Official Visitors (Mental Health), the Nurses Registration Board, the Ombudsman (matters other than Health), the Medical Council, the Anti-Discrimination Commissioner, the Commissioner for Children, advocacy organisations and others. Each of these bodies respond to, and variously report upon, matters raised by individuals and the wider community. These bodies respond to individual and consumer concerns with respect to services. Doing so, they are particularly well-informed – evidentially-grounded – both as to failures with respect to systems and as to those aspects of systems which work well. Advocacy Tasmania submits that any CCE strategy should expressly acknowledge the roles of existing mechanisms and commit to their maintenance and strengthening. While processes such as those outlined in the Paper clearly have important roles, it is critical that they be understood as additional, not alternative or ‘instead of’.<sup>5</sup>

## **2. What do you think are the benefits of consumer and community engagement in decisions about health and human services?**

From a cost-benefit/cost effectiveness perspective, consumer engagement is central to moving toward ‘whole of system’ thinking because, **properly implemented**, it is a cost effective process which identifies the service needs of consumers and identifies the

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<sup>5</sup> The recent Commissioner for Children’s Colloquium #2 examined a number of these approaches in considerable depth, with respect to child protection and out of home care issues – Hobart 15 May 2009.

service gaps. In public policy terms there are a number of drivers of engagement strategies. These include:

- consumer knowledge and experience of services provides unique qualitative information on the delivery, impacts and outcomes of service provision. Consumers provide a “bird’s eye view” of service systems. Ask the customer;
- better knowledge enables better, more cost-effective services;
- engagement respects the civil and human rights of consumers to have their views heard and respected. Respectful engagement tends to provide better therapeutic and social outcomes, further resulting in cost savings. As above, internationally these factors are increasingly understood as essential, central to service provision, both functionally and legally.

It remains engagement strategies also entail certain risks or potential dis-benefits. They are costly and time-consuming in terms of development, training and other aspects of implementation. As below, they require clarity as to expectations and objectives. Failing commitment, they will be perceived as tokenistic and have adverse results, not positive. A failed system wastes the resources committed and incurs the costs of re-engagement. A system which does not adequately engage – ‘drill down’ in sufficient depth or complexity, respect and reflect partnership – risks cosmetic superficiality. It is also of concern that the Paper flags a ‘one-stop-shop’ Peak Body approach. Such mechanisms require care. They are bureaucratically and politically popular for a range of reasons which do not necessarily reflect good public policy and practice. For example, they may readily become unrepresentative, captive of interest groups, subject to commercial and or political pressures and distortions with respect to appointments and independence, unable to exercise any real (as opposed to apparent) influence. On one hand, they risk tokenism and superficiality. By other dimensions, they risk commercial and political distortions in devolved-delivery environments. Such distortions are not in the interests of consumers or the community at large.

### 3. What principles do you think underpin engagement?

It is difficult to criticise the abstract principles outlined (p7) but their practical effects lie in the detail. Perhaps what is important here is to distinguish guiding values or principles from operational principles or understandings. From our perspective, there are two overarching guiding principles. These are, first, legal considerations of rights and secondly, those of sound economic management and governance. In practice, the two sets are intimately interlinked.

Legally, good public policy should – and increasingly *must* – recognise human, civil and economic rights. From a rights perspective, consumers have the right to expect timely services of appropriate nature and quality, and to be protected from neglect, negligence and abuse in these terms. As a matter of human rights, consumers are entitled to have their wishes consulted and respected with respect to fundamental rights and freedoms as provided by law – for example, to liberty, to freedom from unlawful restrictions, to bodily integrity and freedom from treatment unless consenting, to choice of treatment.

International instruments specifically elaborate and extend these rights and protections to especially vulnerable groups – the young, the elderly, the disabled, those with mental illness. Civil and economic rights extend these lawful expectations to matters such as food, shelter and education. Holistic, ‘person-centred’ approaches to service delivery recognise that in many cases deficiencies in one service area have profound impacts across others. Meaningful engagement processes respect these rights, and assist identify these deficiencies.

From management and administrative perspectives, there are two principal guiding understandings. First, it is internationally recognised, beyond question, that consumers provide understandings and insights into the operations of services that no others can provide. A service delivery mechanism is administratively negligent insofar as it ignores this information. Secondly, the adverse economic impacts of failure to provide adequate services is increasingly widely understood across all jurisdictions. Here ‘adequate’ includes sufficient, appropriate, targeted, necessary, timely, coordinated – all qualities which can be routinely informed by appropriate consumer engagement. For example,

recent European research suggests '[m]ental ill health costs the EU an estimated 3%-4% of [annual] GDP, mainly through lost productivity'.<sup>6</sup> Similar figures are to be found across jurisdictions in a wide range of service areas. As an over-arching principle, not properly accounting, and addressing, the impacts of service deficiencies is poor governance.

## **Principles - converting the abstract to the operational**

As above, the processes of engagement foreshadowed are relatively recent in policy and planning terms. The concepts and mechanisms discussed represent significant change across very diverse sectors. Change will encounter significant historical baggage in some respects. For example:

### **Principle 1: Trust**

There is a world of difference between trust and mutual agreement. The former will require significant remedial action in the present environment, even given agreement. Trust must be earned, and is easily lost.

### **Principle 2: Respect**

It is not abundantly clear from the Paper that we are discussing equal contributions. For example, we have not yet clarified processes or parameters in any given respect. Are we discussing the right to be informed, to inform, to design and implement, to decide resources, objectives, methods? If not equal contributions, why not – and is the discrepancy respectful?

### **Principle 3: Openness**

Presumably consumers, carers and the community are already quite comfortable with having their ideas considered (and acted upon). The success of engagement will rest on developing and maintaining their trust that this is in fact the case.

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<sup>6</sup> EU Green Paper, *Improving the mental health of the population: Towards a strategy on mental health for the European Union*, EC Health and Consumer Protection Directorate-General, COM (2005), 4.

**Principle 4: Equal Opportunity**

It may well be that an important function of an engagement process may be to determine a decision-making process, rather than to receive it as a *fait accompli*.

**Principle 5: Advocacy and Support**

It is certainly critical that participation is valued, supported and resourced at all levels.

**Principle 6: Responsiveness**

Amen. Engagement will certainly require a complex, multi-layered mix of approaches to a wide range of needs, perspectives and priorities. The difficult questions are how, what mix, and why?

**Principle 7: Shared ownership and accountability**

Ethically and in equity, responsibility can be shared only insofar as it reflects the power to influence. Where power is unbalanced, responsibility is also. Monitoring and evaluation are usually technically complex, resource-intensive and require specialist skills both to undertake and to analyse.

**Principle 8: Dissemination**

Presumably dissemination will most be required where consumers, carers or community did not significantly share in (where not deeply engaged with) a decision-making process, and those processes were not openly discussed and reported.

**Principle 9: Evaluation**

See Principle 7. Continuous learning is certainly desirable, but requires considerable commitment of resources and skills. Without this, any information disseminated will be disinformation.

## Operational Principles

There are a range of considerations which should inform thinking at all stages of design and implementation of these engagement processes. These include:

- recognition that consumers have expert knowledge and experiences which must be valued and purchased;
- at the same time, recognising that many consumers will require training in aspects of these processes, and some will require very sophisticated assistance and supports;<sup>7</sup>
- ensuring clear and agreed terms of reference including purpose, scope, responsibilities and accountabilities. Particularly, ensuring representative consumers adequate opportunity and means to report back to and consult with any group represented;
- a fundamental expectation and acknowledgement that consumer engagement should be accurately costed, fully funded and actively sought as an operational priority;
- acceptance and awareness that it is critical to match engagement processes to target objectives (cohorts, sub-populations) as necessary and facilitate these appropriately;
- awareness of the dangers inherent in unrepresentative approaches. This includes, for example, ensuring that individual and minority engagement is not displaced by administratively more simple (and less expensive) group process;
- acceptance that consumer engagement should be fully informed at all points. Shared information must be relevant, accurate and timely;
- acknowledgement that the quality of engagement generally reflects the length of time given to the process;
- acceptance of the requirement that engagement must be incorporated into legislation, as increasingly the case internationally;

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<sup>7</sup> Such as those Advocacy Tasmania provide regularly to our clients, and those of other organisations. See Appendices.

#### **4. Does our approach to engagement make sense for Tasmania?**

As indicated above, we are disappointed the Paper provides little guidance as to how or why the approaches discussed may fit the unique Tasmanian environment. This is particularly important given that the Paper clearly flags an inclination or intent to impose upon a health care framework both a health care and a human services consumer engagement function. To the best of our knowledge, this is not an approach which has been adopted elsewhere, and its feasibility is thus unproven – there is no evidential base. This approach gives rise to unease about the Agency's commitment to sufficient future funding and proper resourcing of a consumer engagement process. It could be seen as calling into doubt the sincerity of the process, suggesting tokenism, the implementation of fashionable policy and a possible lack of respect for the diversity of the interests and needs of the Agency's clients. Also as above, we are concerned that the Paper does not acknowledge existing engagement mechanisms we consider critical adjuncts to the types of processes it outlines.

A further concern follows from the complexity of many of the issues we address on a daily basis. At various times over the past decade government has identified and promoted the need for a 'whole of government' (WoG) approach to service formation and delivery. Advocacy Tasmania applauds this approach, despite the notable lack of commitment and unevenness of application to date (with certain laudable exceptions). Most recently, the 2007 DHHS Agency Collaboration Strategy has achieved some useful results with respect to the linkage issues identified, but now appears to have been discarded or de-prioritised. We are concerned that a major failing of services we frequently encounter, on behalf of our clients, is the failure of multiple service providers to 'see the client whole'. What is frequently missing is a person or family centred approach which recognises the critical functional interdependency of some clients/client groups on a range of services. In these cases failure of one element of provision may have catastrophic effects on all other aspects of those personal or group circumstances – for example, homelessness, inability to access transport, and so forth. It is our experience that in such cases agencies and individual (devolved, contractual) service providers frequently lack over-

arching knowledge and may be reluctant to accept responsibility to allocate resources. Case management and responsibility is accepted by no-one. In such cases clients frequently crash, not slip, between the service silos. We are concerned that these complex and exceptional needs mechanisms have operated inconsistently in the past. We are concerned that a holistic Health and Human Services engagement strategy may narrow the focus to the Agency alone, acting to further divert attention from such needs, rather than whole of government. This would be regressive in the extreme.

#### **5. What do you think needs to be in place for consumer and community engagement to work?**

In this respect we re-draw your attention to the guiding and operational considerations discussed under Question 3. Clearly it is to be expected that any processes entertained should have regard to these matters and other factors such as culture and ethnicity, gender, geographic location. There must be an agreed, clear and strong framework which recognizes and addresses the diversity of needs and requirements of those serviced by the Agency and its agents. This framework must also address the particular vulnerabilities and dependencies of some consumer cohorts. To reiterate, the Consultation Paper is deficient insofar as it fails to present any proto-typal thinking to shape the transition from approaches elsewhere to possible Tasmanian options. This work remains to be done.

#### **Conclusion**

From a technical perspective, the task posed is challenging. In its broadest sense, the term health consumer refers to the whole population, ie all those who use the health system, past, present and future. This complexity increases if human services are included. It is hard to imagine other than a complex web of mechanisms embracing such diversity, in any meaningful terms. It remains as an advocacy body concerned with those often particularly vulnerable - the mentally ill, profoundly disabled, the elderly and the young – Advocacy Tasmania is concerned that these groups and individuals will not fit generic models. They will require particular and specialised engagement processes – such processes as ATI has developed and delivered now over some years. Historically

they also require heightened awareness and protections, which extend well beyond processes of consultation and information. Such issues as involuntary detention and treatment; care and treatment of the profoundly disabled, out of home care and treatment of children require especial care and protections. Arguably the priorities of government should address existing inadequacies in these respects, at least as urgently as the types of measures put forward by the Consultation Paper.

As already noted, we are disappointed that we find the paper gives a sense that the Department has already determined its strategies for consumer engagement. We sincerely trust this is not the case, and look forward to further involvement in this difficult but important process. Advocacy Tasmania strongly supports meaningful engagement with our mutual clients as a *modus operandi*, and is committed to continuing to assist achieve these aims. It remains the Consultation Paper could have offered more defined substance for consideration, in language better adapted to consumer understanding. What are Tasmania's options? What are the barriers and enablers? How might responsibilities be distributed? How will the Agency guarantee priorities, funding, resources, time, support, training and infrastructure? The first step of consumer engagement is the provision of high quality detailed information to consumers, appropriately to their circumstances and capacities.

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## **Appendix 1 – “YOUR CARE, YOUR SAY”**

### **SUMMARY OF CONSULTATIONS CONDUCTED BY ADVOCACY TASMANIA INC IN MAY 2009 WITH BOARD MEMBERS/CONSUMERS AND ADVOCATES**

#### GENERAL COMMENTS

- The language of the paper was not liked, especially the use of “we” which was thought to be patronising in tone and contrary to the whole principle of consultation and engagement by having the “we” and “us” or “them” and this separates the key players from govt depts.
- It sounds like all rhetoric and motherhood statements.
- This is not really a consultation paper - it informs rather than seeking input.
- Without any indications or accountability it is a promotional or spin document not a consultation paper. Sadly, it is a marketing document and not a real consultation document.
- The paper tries to create an illusion of developing a so-called consultation mechanism and proposes a tiered model which is easiest for govt to consult with but does not necessarily result in true engagement or consultation.
- Governments like having peaks with which to consult or other representative groups because that is easiest for them but does not necessarily provide them with a good consultation or engagement process or with the most useful information.
- The content of the paper tries to capture or control the agenda from the outset rather than seek wide ranging input.
- The 5 questions asked are non-questions really, they lead all the answer in the positive so there is an appearance of agreement with the proposals.
- Questions 1-5 are seen as a very cynical exercise because they do not encourage broad debate but seek to control the agenda.
- Are we going to make any RECOMMENDATIONS in our paper?

#### THE QUESTIONS

##### Question 1

Who is going to say “no” to this question? This is a question that need not be asked or answered in the 21<sup>st</sup> century.

##### Question 2

The right process has to be employed or we will not get the benefits sought.

##### Question 3

The way the questions are structured, it would appear this is seeking a stated preference for some of the proposals of the paper.

##### Question 4

The Canadian Model was not favoured.

The paper does not outline some of the consultation or engagement processes currently being used (some it would appear very successfully) within the state and nationally.

##### Question 5

Consideration of some of the broader issues identified below:

- There needs to be shared ownership of the process and shared accountability.
- There needs to be internal and external and independent review mechanisms.

- The risks of consumer groups being high-jacked by a few.
- The Victorian Model has three types of engagement: consumer groups, local government and consumer consultation, and government advisory groups.
- There are no specific indicators or accountability mechanisms proposed.
- We have gone backwards since the 1990s in relation to consumers having a say directly with depts. They used to be accessible and now they are locked away and inaccessible. A proposed process does not take the place of being open to hearing from all consumers.
- This process is proposed for the govt H&HS sector but there is no mention of including NGOs and private sector service providers in the process.
- This is a fundamentally, extremely important process which requires real attention to consultation and engagement at this early stage in order to make it work and this is not well facilitated by having a response date of 12 May 2009, a draft strategy by June 2009 which will inform the final consumer and community engagement strategy, which go to the State Govt in August 2009.
- There is an unacceptable narrowing of the debate by asking people to respond to 5 questions rather than comment on the broader issues and processes that need to be considered first.
- As there is a danger of a “whole of govt response” (as with Health and Human Services) in any context in that some things cannot be “lumped together” without losing the finer detail required. Similarly, taking the narrow focus of citizens having their say in just the areas of Health and Human Services and not all services also has its risks. Why not find a model to consult with the wider community in relation to all govt services and govt funded services?
- Most people don’t see themselves as consumers, but as community members or citizens. However the definition of citizen in this paper is seen as inaccurate – all citizens or community members have affiliations and that is why they want to have a say. The definition given for “citizen” better suits that of an independent representative. Being a representative and a citizen are two very different things.
- We should not want to just consult with service users and frequent service users - we need to consult with all the community because the services are supposed to be designed for all the community.
- It appears that they don’t want to engage with those who represent consumer or community interest groups on particular issues but they are the people who know the issues about which they need to be informed.
- The paper is more about infrastructure and not really about “engaging with the community”.
- Need to address how our consumer groups can have real engagement and input into the process.
- How the govt sees engagement is not thought to be the same as what the community sees as engagement.
- There needs to be some safeguards or positive discrimination to ensure that some specific groups do have input - those less able to represent their views easily.
- The need for consumer involvement in Review and Evaluation not only in Having a Say.
- Review and Complaints Mechanisms are very well informed and would be a great resource for this process.
- When consumers engage with Advocates, Complaints Bodies such as Health Complaints Commission or Ombudsman, or Review Bodies: they provide a lot of very valuable information about what is working and what is not working. One of the best ways to find out about how to make the system work better would be to amp up the oversight and protective bodies and use the information they obtain when they engage with consumers to better inform the service sector.
- Equity and equal opportunity is never really possible – therefore, there needs to be processes that ensure that more vulnerable groups of those who have trouble being heard have a voice.

Group Facilitated 1 May 2009:  
by Rebecca Thompson

**Appendix 2 – “Your Care, Your Say”**  
**SUMMARY OF CONSULTATIONS**  
**CONDUCTED BY ADVOCACY TASMANIA INC**  
**IN MAY 2009**  
**WITH CONSUMERS WHO HAVE INTELLECTUAL DISABILITY**

The questions were put into plain English for greater understanding of people being consulted with, and the responses written below are their words

**1. Do you think the Government should talk to you about your services?**

- Yes they should!
- They should talk to us (people with disabilities/ pensioners) about the rising cost of food as costs us a lot of money.
- (One service is) the Government gives us our money i.e. pension.
- Several said they don't really know what Government services there are.
- Do know about the new Accident and Emergency section of the Royal Hobart Hospital as have been there with another person with a disability.
- Wish we had a better taxi service - as we get stranded and taxis don't turn up – problem is when you book it, it's not ( directly) with the driver and they don't know where we are ( problem is explaining location to person on end of phone).
- Some clients knew some of the government services available such as dental, day support services, service coordination, pension and mobility allowance, public transport, taxi subsidies.

**2. If you could tell the Government about services, what would you want to tell them?**

- They (the Government) wouldn't understand what people with disabilities are talking about and what we are going through.
- Public transport – not many buses on a Sunday and don't come on the right time or as timetable says.
- They just don't understand us.
- Government doesn't understand when we need extra support & help – and there is not enough money to pay for more staff support and that's a problem.
- Staff only come when they are rostered on but not when they are sick (which means no support at times for us).
- People with disabilities don't like to go to hospital – not comfortable there and they (hospital staff) don't understand us.
- Want more money with our pension then could save and go on a holiday.

- It's the Government's job to tell us (what's going on) and if they don't we won't know what's going on.
- If there was a complaint about a service we would need help from an advocate to complain.

### **3. How would you like to meet and be consulted with by Government**

- We'd like to meet in small groups of say 4 – 6 people, with someone there to help us like an advocate or our day support coordinator – not at a very big meeting ( as don't know what to say in a big group) and not just 1 person at a time (intimidating).
- If had a companion card, a support worker could come along to help me.
- Any paperwork needs to be in big print to make it easier to read and with pictures (for people with low literacy skills) – if people can't read they need someone to help them understand the written information.
- Want a special support person with them as some things might be very personal and private.
- What about people who can't see or can't hear – need special help – would need to use sign language for the deaf.
- Meetings need to be informal – with a cuppa and afternoon tea.
- If going to a meeting with government means missing work, then need to be paid to attend and have transport supplied (if can't use public transport) and paid for eg taxi voucher.
- Night time meetings too hard for people with disabilities – needs to be in day time and suit peoples special needs .
- Would like the Government people to come and see us – would be good if the big boss like PM Kevin Rudd or Tasmania's Premier Bartlett or even Julia Gillard could come out to talk with us – if they did come we could have a BBQ with them and show them how things run.

#### **General comments**

- Engagement with Government needs to be a **joint** process.
- Bit hard to engage with government – doesn't seem to work.
- When there are changes to services we just get a letter – no discussion with us.
- If Government wants to "engage" we need time, to get questions and have them explained - need preparation time and support, before going to any meetings

Conducted 12 May 2009 by:  
 Chrissy Jamieson  
 Jane Blake