

## **EXECUTIVE SUMMARY**

This (summarised) version of In Our Own Words outlines key points which arising from an extensive piece of consumer based research<sup>1</sup>. The report is comprised of two parts. Part One draws on 14 consumers who have sought advocacy assistance from the Health Consumers' Council in the recent past and who agreed to be interviewed about their experiences in the Western Australian health system. The transcribed interviews provided primary material which allowed a thematic analysis of issues to be undertaken.

The key themes emerging from the interviews are:

- **Consumer experiences of adverse events and how these might be better managed**
- **The crucial interplay between communication and treatment**
- **The loss of faith in practitioners and 'the system' which results from such experiences**
- **The emotional and social effects of adverse events on consumers**
- **Qualities of 'good' practitioners**
- **The influence of provider assumptions on subsequent clinical diagnosis and treatment**
- **The desire to be treated in a more holistic manner – the 'down side' of specialisation**
- **Problems within the hospital systems**
- **The experience that quality health care is compromised due to ones public or private health insurance status**
- **A concern that identified system problems within the system are not used to drive improvement and a consequent concern for other members of the public**
- **Determined pursuits of justice from those who feel let down by the Western Australian health care system.**

Part Two is comprised of quantitative research findings from 169 advocacy cases over an 18 month period. These findings confirm the qualitative finding that issues to do with communication and treatment are extremely important to optimum health care. (Complaints in these two categories are the most frequently recorded. Across all service provider types (public and private, psychiatric services, General Practitioner services etc) complaints about treatment and communication combine to feature between 60 – 81%.)

The key finding of this research is that in order to address ongoing issues in complaints and to restore the communities faith in the Western Australian health care system considerable effort needs to be made to make excellence in communication pivotal to health service provision. Strategies that allow practitioners to 'walk in the patients' shoes' may be the best method of achieving this outcome.

## **RECOMMENDATIONS**

This consumer focused research recommends that:

- Health service providers and consumers in Western Australia would benefit from recognising and acknowledging the importance of good communication to optimum health service provision.
- Individual practitioners need to take responsibility for their own standards of communication with consumers to whom they owe a professional duty.
- Structurally, health services need to build in the capacity for clinicians and practitioners to spend extra time and attention providing information within professional, respectful relationships with consumers.
- Endorsement by health services and practitioners of the principle of Open Disclosure in the

event of an adverse outcome and the need to provide redress where appropriate.

<sup>1</sup> The original research contained many more (often extended) direct quotes from the interviewees which clearly indicate the consumer experiences and how the identification of such themes came about. For the full report contact the Health Consumers' Council on (08) 9221 3422.

## **INTRODUCTION**

Consumers and carers approach health services with an expectation to receive treatment or cure from practitioners and a health system that will respect their needs and interests.

When these expectations are breached, either accidentally or negligently, a complex process begins of defining what the grievance is and where the cause lies.

Consumers who enter a process of seeking redress for a wrong that they have experienced, undertake their own information gathering and analysis of the situation they face, often when sick, injured, upset or aggrieved.

This report provides a unique insight into the consumer side of the healthcare equation. The commonality of themes in a wide range of consumer and carer experiences attests to the systemic nature of both the problems and solutions in healthcare. It is both objective and subjective, drawing on both observation and emotion to reach conclusions about the factors that contribute to their situation.

\* \* \*

The Health Consumers' Council is an independent community based organisation representing the consumers' 'voice' in health policy, planning, research and service delivery. Part of the core work of the Council is to provide an advocacy service for health consumers' experiencing difficulties in the health system. The organisation was established in 1994 in an effort to provide Western Australia with a peak consumer body to represent the community's voice on health and to partially counter the powerful lobby of medical practitioners.

Through this research project, the Health Consumers' Council's aim was to examine the trends of complex advocacy cases in order to see what recommendations could be provided to the Health Department, the hospitals and the health services to help contribute to optimum safety and quality in WA health settings.

## **METHODOLOGY**

### Qualitative Research.

Open style interviews were conducted with 14 interviewees. Guiding questions and a 'desktop mind jog' were used to help direct the consumers' retelling and analysis of their experience in the Western Australian health system.

### Quantitative Research

A statistical analysis of 169 individual advocacy cases which had been undertaken by Health Consumers' Council advocates between January 2000 and June 2001 was also conducted. This involved the extraction of information such as

- Complaint Category (Treatment = 6 subcategories; Communication = 6 subcategories; Professional Conduct; Rights; Access = 7 subcategories; Costs = 7 subcategories; Administration etc.)
- Service provider type (Public hospital, public mental health hospital, General Practitioner, Private Physician etc)
- Gender of consumer and provider (where applicable)
- Postcode

in order to provide statistical data on such determinants.

#### Anonymity of Interviewees of paramount importance

A fair amount of direct dialogue from interviewees was used in the (full original) report. Great effort went into protecting the identity of individuals whose interviews have provided the raw material for the final report. No identifying features have been included in the final report; names, gender, doctors, illnesses have all been changed in order to ensure the anonymity of the consumers as well as that of service providers.

#### Thank you to participants:

It is a humbling experience to meet and talk with people who have experienced such hardship through involvement with the medical system, and who reveal their resilience, perseverance, and commitment to the pursuit of justice and who are willing to revisit those experiences in the hope of adding to efforts to improve the health system for others.

The Health Consumers' Council offers its sincere thanks to participants for their generosity of time and spirit in agreeing to participate in the research. The research would not have been possible without the unique and invaluable consumer contributions it draws upon.

## **PART 1 – QUALITATIVE RESEARCH FINDINGS**

### **Chapter 1**

#### **WHEN SOMETHING GOES WRONG**

An incident resulting in harm to a patient receiving health care, is known as an adverse event.

The interviews highlight common themes and a pattern of steps after an adverse event occurs, which results in the health consumer losing faith in the medical fraternity and the bodies overseeing health professionals (the Medical Board, Office of Health Review, professional peers) so that the courts end up being the measure of last resort in the aggrieved and damaged consumers' pursuit of answers and justice.

In summary, the cases brought to the fore a common pattern of events for the consumer. These were:

- A) An adverse event occurs – “We knew something was wrong.”
- B) Consumer attempts to discover what had happened.
- C) Difficulties obtaining information.
- D) No apparent additional care.
- E) Doctors close ranks.
- F) ‘Bad’ Adverse Event management leads to legal action.

The following is a sample of consumer quotes about their experiences in the health care system in relation to adverse events.

#### **A) Adverse event occurs– ‘We knew something was wrong.’**

"After asking multiple questions in the next week, (the surgeon) actually admitted that he did it, which was fine...we understand that things happen, and that is that. But basically after that...he just left you, basically to die.

**B) Consumer Attempt to try to discover what had happened.**

"It was a lot of umm...a lot of putting questions to him. He didn't volunteer any of the information. And even after asking the questions once or twice, he wouldn't actually come out straight away and say it." Yeah, it is just the attitude like, 'I haven't done anything wrong.' It's like he (the doctor) couldn't admit it...he just couldn't admit that something had gone wrong. It is just basically, you know, oh...they give you a bit of information...it's like feeding ducks, you know, throw them a bit of crumbs here and there but don't give them the whole story because...they might make something up from the whole story

**C) Difficulties seeking information**

"It was never documented. We asked for some FOI information...to be sent to our G.P. Just to get some idea. Because I really wanted to know if they cut my (body part mentioned), if they opened the (body part) up. You know. So you have got some idea later on in life if you have any complications. There was nothing written down. It just...there wasn't anything. And basically...Basically the information that we got was that I presented as an emergency case at the hospital... An operation was done. There was some bleeding. I was then transferred to a private hospital...and then, subsequently I had a (complication). That was cleared and I went home for recovery. And that was it.

**D) No apparent additional care**

"He didn't do anything, he didn't... try to make amends, try to make it better. He didn't want to know him. I was like, 'Quick get out of my hospital before anything else goes wrong so I don't have to deal with it.'"

**E) Doctors close ranks**

"The second surgeon who was going to look after him actually assisted in the very first operation....So I just thought that it was going to be a whole complete...'OK you cover my back I'll cover your back,' kind of thing, and I decided, OK this is enough."

**F) 'Bad' Adverse Events Management leads to Legal Action.**

"I had to go and litigate him for all the deceit and misleading and causing me the problems all along...and not explaining himself...I had to hit him for something. And of course I believe in principles. I felt the righteousness to...I had to litigate him....because they never came forward and told us anything...If someone causes you problems you expect the person to come forward and say... 'Well I've caused you the problem what can I do to help you out'...and they never did, and (so) that's what I had to do."

**Consumers' views on how an adverse event might be better handled.**

"I think....like we're human, we understand people make mistakes. Well things happen....everything doesn't always go to plan...We would have liked to have been told exactly what happened of course...you know it has happened...there is nothing you can do to undo it. I would have expected that (the doctor) looked after him, and...kept a close eye on him....to say 'OK I'm going to make sure this guy gets better, you know, I'm going to make sure he gets out in one piece, and it's not going to affect him for the rest of his life.' We would have been happy...if he had...said, 'Let's do some tests, let's see if you have got an infection.' He might have been able to treat him quicker. He might have been able to do the (second) operation quicker"

**Discussion:**

Medical care involves a technical procedure in the context of a human interaction between the

health service provider and the patient. When something goes wrong and communication between these two parties does not take place, the transaction is not seen as completed. Explaining the error, face to face, with the person/s who have been affected, is what consumers expect as the minimum, reasonable duty that the practitioner has towards them. When this does not occur, the consumer is left up in the air, left to draw their own conclusions, injured further by the practitioner's apparent neglect of the relationship with them.

## **Chapter 2**

### **THE INTERPLAY BETWEEN TREATMENT AND COMMUNICATION**

A majority of advocacy cases brought to the Council involve complaints which highlight complex problems brought about by the interplay between communication and treatment issues.

The interrelationship between these two complaint categories is illustrated by the quantitative component of this research paper (See Part 2) which reveals 40.8% of total complaints across service provider types involved treatment issues, and 21.6% involved communication issues. This makes up a total of 62.4% of all complaints relating to communication and treatment issues.

Within individual service provider types, complaints about treatment and communication together consistently made up between 60% and 81% of all complaints.

The 14 advocacy interviews highlight the fact that communication problems between consumers and providers frequently lead to, or exacerbate inadequate treatment and related issues. Every interviewee revealed that the communication/treatment issue had been problematic for them.

The experiences revealed through the advocacy interviews highlight various problems in the treatment and communication conundrum. These include;

- A) Service provider 'arrogance.'
- B) Dismissive providers.
- C) Insufficient information.
- D) Providers blaming the patient.
- E) Problems arising from consumers asking questions or challenging doctors.
- F) Provider resentment at consumer involvement in their own treatment.
- G) Consumer/carer involvement in treatment punished/ignored.

These shortcomings in communication (outlined in detail below) compound the negative impact of inadequate clinical treatment and add a personal affront to the physical injury experienced by the patient.

Communication issues are presumably seen to be a 'soft' or secondary issue to the primary issues of clinical diagnosis and treatment. Communication and treatment which leaves consumers feeling invalidated, unheard, and uncared for, undermines faith in professional practitioners and additionally impact's adversely on individuals who are already physically unwell.

#### **A) Consumers' experiences of service provider arrogance**

"I tell you, I am not impressed at all...with the...lack of communication, arrogance...particularly if you don't bow and scrape and say yes sir, no sir, three bags full."

#### **B) Dismissive Providers**

"I thought (that) it was (a particular health problem) from the very beginning, and I would say that to every doctor I saw, and it was dismissed, until I saw the champion (in a Sydney hospital), which was nearly 10 years after I first got (the symptoms), he was the first guy who said, "Yes I think you might be right."

**C) Refused to speak/respond to me/my letter**

"I could not get past the clerk who answered the phone. The clinical co-ordinator and the executive director both refused to speak to me"

**D) Insufficient information**

"I was left lying on the trolley for three hours, I still hadn't seen anyone (since being admitted the day before, except the resident). I wanted to see an anaesthetist...to warn them that that it was going to be extremely problematic to do an anaesthetic unless they know what the previous situation was. So I was panicking after three hours...I hadn't seen a surgeon for pre surgery or an anaesthetist... I was put under before I could explain 'Stop find out'."

**E) Blaming the patient**

"And the tendency to blame the patient. You know...(rather than to say we don't know...)"

You know - to call me an opiate...you know...an opiate hunter, whatever you want to term it...someone who is just after opiates..."

**F) Problems arising from asking questions or challenging doctors**

"And if you challenge it, they don't like it. In fact if you challenge them at all, you get...you tend to get...put into a category of being a difficult patient."

**G) Consumer/carer involvement in treatment punished/ignored.**

"I was discussing further options of treatment for him that may have been available...phoning the US and all sorts of people to find out what other options were left for him. I was talking to the doctor about options for treatment, and he got shitty with me... that I was there, you know, suggesting that maybe he wasn't treating him properly and he withdrew (his) services. And that is why he finished up on (another) ward."

**Discussion:**

These quotes highlight the importance of health service providers recognising that communication plays a fundamental role in the provision of good service and health care. Good communication is not a secondary issue to clinical treatment, an additional 'extra', but forms the foundation of good relationships, of professionalism and therefore of optimum health care in clinical settings.

Consumers expect to be **acknowledged, cared for, respected, informed, responded to, consulted with and involved in treatment choices concerning their bodies**. In short, they expect to be involved as a member of their body's treating team.

Communication involves listening well with full attention given to the patient who is before the practitioner. Role plays may be one way to achieve a 'stepping into the patients shoes' to gain an understanding of the particular issues for them. This would involve the participation of providers, in the consumer role, and professional actors who have been coached by aggrieved consumers as the service provider.

**Chapter 3**

**LOSS OF TRUST AND FAITH IN PRACTITIONERS and IN 'THE SYSTEM'**

Throughout the 14 interviews, there was an overwhelming expression of lost trust in practitioners

and faith in the health system on the part of consumers and carers. This loss of faith is a direct consequence of the consumers' experiences and engagements with practitioners who, they felt, did not always have the best interests of the patient at heart.

It would be reasonable to say that all 14 of the consumers interviewed have had their faith in the health system and practitioners challenged as a result of their experiences.

Below are a series of quotes from consumers revealing deep distrust of practitioners and the mechanisms set up to protect consumers within the health system.

#### **A) Consumer perspectives on loss of faith in Practitioners.**

##### Consumer Report A1:

"Can you imagine when you go for an operation where you trust, you trust...you know... fully to your surgeon and to your anaesthetist and you just wake up with a problem...you don't understand why you have (it) and then when you find out why you have it. How would you feel? It's terrible. My trust was, I feel terrible, you know I feel how can I trust again? It's awful and I think it agh...this is something that lay people don't know..."

##### Consumer Report A2:

"Now during all that time, I thought the consultant was on our side. But I came across the medical notes. They handed them to me one day...I found the consultant had written a dreadful letter to the rehabilitation specialist. No wonder we didn't get into rehab..."

##### Consumer Report A3:

"So I just thought that it was going to be a whole complete....OK you cover my back I'll cover your back kind of thing, and I decided, OK this is enough. And I rang (the surgeon) and said, 'No you are not to have anything to do with us anymore. Nor is your friend. I want this surgeon (of my choice) and that's it.' Because we needed a completely unbiased view of somebody who wasn't going to be like...in inverted comma's 'in trouble'... because just felt maybe, maybe they wouldn't, do the best to make him...better..."

#### **B) Loss of Faith in 'The System'.**

##### Consumer Report B1:

"I truly do believe that the system uses people as guinea pigs, and in this case I reckon he was used as a guinea pig for some surgeon to gain so many hours or to get his hours up. It's like a pilot who flies aeroplanes, you have to get so many hours up. And this applies the same to this system."

##### Consumer Report B2:

"Well the system is quite big...they need work...they need guinea pigs...you know what I mean...like people to use them as the guinea pigs...You can go yourself, even to GP's or anyone, he'll give you something and you don't know what he is giving you. It might be because he won't explain it to you, sometimes they don't explain...so they give it to you...and you take it...and you say...Oh I'm not feeling well...you go back again and they say ohwe'll try something else, or something else...no different...the system is...it's not quite right system..."

##### Consumer Report 3:

"I don't think that there is a real 'system' set up for medical mistakes. There is a readiness to tranquillise for various reasons bringing another facet to the problem and not at all an appropriate way to deal with people who are damaged in their bodies...I am angry that the 'system' allowed this man to practice...him being famous for his

unorthodox procedures post dating me.”

**Discussion:**

The way in which adverse outcomes are dealt with and dismissive and indifferent reactions from practitioners are the key reasons identified in this research for such losses of faith. A focus on improvement in such areas would be well received and rewarded through reduced complaints and greater public confidence in the health system.

Consumer faith in health services and practitioners is a positive and necessary ingredient in the treating/healing interaction. Conversely it can be reasoned that loss of faith works against productive patient-health service relationships. Consumers who have been left with feelings of fearfulness, cynicism and anger will likely take such feelings with them into future engagements with health services and individual practitioners. Prevention of the conditions that lead to such powerful emotions being felt is far better than being faced with the complex task of recovery and redress, for both the consumer and provider parties.

**Chapter 4**

**EMOTIONAL AND SOCIAL EFFECTS OF ADVERSE OUTCOMES ON CONSUMERS**

This chapter brings together responses to the interview question “How did you feel when you started to think things were not going well.”

The common expression coming up in these consumers’ experiences are strong emotions such as anger, stress, frustration, panic; and feelings of being negated, minimised and ignored.

**A) Emotional Effects of Adverse Events in Health Care on Consumer**

Consumer Report A1:

“I was very, very scared. I was in shock for years. Deep shock. I had panic attacks and my family life crumbled around me. The shock and panic turned to outrage and anger and I am...still in that mode. I have had no closure on this and I can’t drop the anger. I am angry ‘the system’ allowed this man to practice...”

Consumer Report A2:

(I felt) “Distressed, abandoned, minimised, negated, umm...and that you know, I had no right to actually access that health service.”

Consumer Report A3:

“Well (I felt) panic. Because you know you could be heading for disaster, and yet people are not listening to you. ...(to) find out why you are panicking. (I wanted to say), “Stop find out”.

Consumer Report A4:

“I went in thee positive, proactive, energetic...I left exhausted disillusioned, cynical, stressed, lonely, unsupported, negative and depressed. I was scared of being punished by the doctors. I felt (hospital staff were biased, prejudiced and judgmental.”

Consumer Report A5:

“I felt very frustrated...ignored...rejected. I am coming to the end of my tether now....”

**Discussion:**

Consumer and carer reactions to badly handled adverse events reflect the harm that such experiences can cause to an individual’s sense of self. Consumers (and carers) can be faced with a physical medical crisis as a consequence of an adverse outcome, as well as a significant affront to their sense of fairness and justice. An adverse event handled well can never make the injury

null, but will leave the consumer more emotionally intact to deal with the adjustments that may need to be made to the effects of such an event.

## **Chapter 5**

### **RESTORERS OF FAITH**

This chapter includes testimonies from consumers who have expressed the negative feelings and losses of faith in the health system (above) and have since come into contact with practitioners who are able assist the consumer to again feel cared for, validated and heard – practitioners we call here the 'Restorers of Faith.'

In short, practitioners who are 'Restorers of Faith' are able to 'walk in the patients shoes.'

#### **Restorers of Faith....**

##### **Consumer Report 1: Explained everything, frankness...**

"Yeah, they were really...they were better than all he (other) doctors that he had. They sat down and explained everything...you know, what wen wrong when his systems failed the first time. 'No he doesn't look good.' You know. They wouldn't give me a time frame, which is normal. I roughly knew anyway."

##### **Consumer Report 2: Thorough, encouraging, patient advocate....**

"A Dr X came, a neurologist...He came to the hospital...very thorough. We were more than pleased with him. He was very encouraging, most helpful andwe thought... 'Great. A long last there is somebody on our side."

##### **Consumer Report 3: Humility...apology...ability to 'equal relate' (sic)...**

"At least he admitted that, and he also admitted that there wasn't anything he could do in the end. And he apologised. He's the only guy who ever did. He's the only guy who ever admitted that there was nothing he could do. And he's the only guy I came across who didn't have that sort of arrogance. Well...he tended to equal relate more than any of the others."

##### **Consumer Report 4: Compassion...**

"Dr Z didn't have an ego problem...he nearly cried to me on the phone, he was nearly crying. Different personality...he was leaving the hospial. And the reason he said he was leaving was, 'I am in the business of saving lives.' So in amongst the ultra egos you do have the individual personality of someone who is genuine, who is compassionae."

##### **Consumer Report 5: Caring and responsive...**

"Caring, responsive suppor that my counsellor delivered in an objective and professional manner."

##### **Consumer Report 6: Respect...**

"Well for start, they can... come forward and apologise first...and make their amendments...whatever the case may be. And treat people with respect, because we're all people...no matter who we are..."

##### **Consumer Report 7: Patient advocacy...honesty...care beyond duty, a treatment plan...**

"This Dr B, he's different. He said, 'Don't you worry, I am prepared to go to court and stand up for you and say what they have done to you.' He is absolutely brillian. He has done more for our child in the 15 months...than what these doctors have in 3 1/2 years. He told her right from the word go, 'What they have done to you is that they have hurt you physically and mentally.' He said 'What my job is, is to sort this out first.' He said, 'I can sort this out and then I can sort that out. But until I sor this out, I can't sort that out.' He sends her emails. Postcards from his holidays."

#### **Discussion:**

The 'restorers of faith' appear to be those practitioners who engage with health consumers in a respectful, humane, compassionate and caring manner. The quotes further emphasise that

consumers see practitioners' communication skills as foundational to good treatment.

## **Chapter 6**

### **PROVIDER ASSUMPTIONS**

A further theme coming through the interviews was the view that incorrect and untested assumptions on the part of practitioners often lead to substandard clinical treatment.

#### **A) Initial Practitioner opinion adversely affects subsequent diagnosis and treatment.**

The first two cases highlight how one health service provider's opinion will often influence subsequent treatment and diagnosis. These consumers felt that their cases were not taken on the medical facts, that they were not given a 'fair go', but that a previous practitioner's opinion overly influenced the diagnosis and/or treatment they received.

##### Consumer Report A1:

"...she did an assessment from it without me even knowing...she copied what was written on the file notes at the hospital (by the doctor) and it was all wrong...the trouble is the file is put away but no one sees it...and it is not always correct.... doctors can write down on your file anything that they perceive or whatever, and everybody else takes it for granted like if you or I look at the file, we'd say OK, well they've obviously seen this guy and this is the problem...but it is not always the case."

#### **CONSUMER SOLUTIONS**

This consumer's solution would involve greater transparency and communication between consumer and provider. The consumer recognises the fact that there will not always be agreement between the provider and the consumer, but it appears it is the accuracy of the records and the transparency issue which is of paramount importance to this interviewee.

"Patients, such as myself, should be resolved to go in and OK everything...Because doctors can write what they like on a form, and another person would take it for granted that that is correct. Well the system could make it available to all patients to view their files and things, so they can basically say 'yes' or 'no' to that. They have got no right of reply."

Interviewer: So it would be good if patients could see their records...all the way through?

"Yes. If they require to see them yes. A lot of people just can't be bothered but I wanted to, I thought it would be interesting to see the file."

Interviewer: So what do you think would happen when things are written that the patient doesn't like or agree with? How would those things be resolved?

"Well then the patient could challenge the doctor or whatever. Have a talk about it. And have it put right, and if it's not put right, well there must be a reason for writing that."

#### **B) Further Assumptions on the part of Practitioners**

##### Consumer Report B:

This carer felt that the doctor assumed that the patient was wrong and not making sense because of a belief that the patient was getting dementia, when this was not the case at all.

"The registrar said, 'You don't know what you are talking about. You are losing your mind.' (The patient responded) 'Would you please read the notes...you will find that in the notes.' ...the registrar flicked through the notes and the patient was right and the registrar was the one who was incorrect. They were trying to say she was getting dementia and that she had lost the plot...the registrar had said she was losing her mind and she was going to die and there was no point in treating her...they wanted to put her in a nursing home down (in the outer suburbs)"

### **Discussion:**

Reports that assumptions held by practitioners affected the treatment received is concerning. These consumers would understandably ask that they are approached and assessed by providers on medical evidence and without prejudice.

Some recognition and acknowledgement on the part of health service providers that at times their assumptions and prejudices may affect the quality of treatment delivered, coupled with a concerted effort to address such assumptions through improved communication strategies - may be two steps towards minimising the influence these opinions have on the care given by service providers.

## **Chapter 7**

### **TREATING THE WHOLE PERSON**

Many of the interviewees identified that health service providers tended to overlook the whole person and failed to see outside the scope of their particular speciality. Consumers highlighted that the somewhat myopic viewpoint of specialists may become part of the problem when it interferes with a holistic view of the individual.

Following are examples of interviewees who raised this issue of their own volition.

#### **Consumer Report 1:**

"The (original illness) was the dominant diagnosis for the treating team and the rehabilitation (which was made necessary) as a result of side effects of drugs - was overlooked, sidelined and blocked. There was the prognosis that she was going to be a quadriplegic. And so 'she was a quad,' and they weren't interested in rehabilitating her...."

**Consumer Report 2:** Treatment of one physiological 'system', and not the other, which, it seems was the cause of the problem. The change of treatment reportedly saw improvements within a matter of days. This was following four months of hospitalisation. The patient was discharged one month after the new treatment was initiated.

"They were trying to alleviate the fluid situation (through various methods) rather than treating the (source of the problem)....I had a phone call with (a specialist in another area of expertise) for the very first time, who said (that the consumer's health problem was due to problems in one particular organ and not the physiological system which had been the treatment focus for the past 3 months.) He owned up to the fact that he wasn't being treated properly. And we should change focus and redirect all efforts to try and improve the function of (this particular organ,) which they hadn't done previously"...

### **Discussion:**

These carers indicate that they would have liked their loved ones to be treated and viewed in a more holistic manner. (The rise in demand for naturopathic treatments across the western world could also be an indication of individuals' desires to be viewed and treated in a more holistic manner.) The role of specialists is not in question, but more there is a desire for the specialist to be more open to lateral thinking when treatments do not work, or when diagnoses are difficult or when problems arise.

## **Chapter 8**

### **HOSPITAL SYSTEMS**

92 out of 169 (54.4%) individual advocacy cases brought to the Health Consumers' Council in 18 months between January 2000 and June 2001 related to Public Hospital settings.

Most complaints about public hospital settings (excluding mental health settings) involved issues relating to; treatment (37%), communication (20%). Complaints relating to treatment and

communication issues therefore made up a total of 57% of all complaints in this provider category. Complaint categories with smaller numbers of complaints in the public hospital sector were;

access (10%),  
professional conduct (5.7%)  
discharge (5.7%)  
records (3.6%)  
administration (2.8%)  
rights (2.1%),  
admission (1.4%)  
costs (1.4%)  
consent (1.2%)  
and other 6.3%.

This chapter comprises three sections.

A) The first looks at consumers' conclusions from the treatment they received at the hospital, that the providers felt that they had 'no right' to access the service.

B) The second section looks at problems within the bureaucracy which contributed to the carer's problems and the consumer dying away from home.

C, D & E) The third section involves systems issues consumers have spoken about during the interviews. They offer unique perspectives on how increased planning and lateral thinking and discussion of treatment options might reduce costs associated with hospital care.

#### **A) 'No Right' to Access Service.**

Two consumers spoke (without prompt) about how they felt they were not entitled to treatment at the hospital involved in their care. One is quoted below

"So, I really did feel...I had no right to actually access that health service. That was the...that was what really made me feel worst. I felt that I had no right to be there. No right to get any treatment, no right to ask for anything. That I was just a bloody old bitch, that was a bloody old nuisance, and just ignore her."

These are strong statements made by consumers who seek assistance for health problems from the public hospital system. The right to access, respect and dignity in health care settings is a fundamental right. Both individuals also felt that they were discriminated against on various civil rights grounds.

It may be worth an honest examination of prejudices and the introduction of methods to attempt to combat such attitudes towards consumers.

#### **B) Problems with the Bureaucracy**

A carer contacted the Health Consumers' Council seeking assistance to have his extremely unwell partner transferred to a rural hospital, so the consumer could be in her home town, close to family support. The spouse felt it was his partners right to die in their home town. The rigidity of bed categorisation and lack of qualified rural hospital staff meant that the consumer was kept in a Perth hospital and died away from home.

### **CONSUMER SOLUTIONS**

The carer had a suggestion for solutions to this problem and felt,

"You should be able to have nurses that can come up , for three months, do a stint up

here (in a rural setting), and if the people get brought home, that is where (the nurses) should be. Not at the hospital...I wanted (my partner) home on palliative care, she was dying...at least she could die at home. The doctor said 'there is nothing wrong with her'. Well she died two weeks later....That is not fair...It boiled down to bureaucracy 'cos the government just didn't care."

### **C) Problems with Practitioners' lack of knowledge of own internal hospital systems.**

One person identified through his experiences that there was a there were not "written, firmly spelt out guidelines as to how to admit people for surgery..."

"I mean obviously it turned out later and I'd suspected it...that...the systems for admitting me hadn't been followed so I didn't have a surgical team, I wasn't admitted into a surgical team. I was admitted as a medical patient. So I decided to redress the problem...after I'd recovered..."

I have this debilitating condition and ever-increasing symptoms, so it wasn't fun and games...I suppose it took about two months for the treatment to kick in so that I was OK enough to sort of start getting back to normal again and the wound had healed up and I'd done (managed the complications arising from the inadequate treatment) and all that suff. It was just a whole heap of stuff...that wasn't necessary for me to get through...if things had worked."

### **CONSUMER SOLUTIONS**

This consumer's complaint and efforts to have the system improvements made did result in changes and there are now written firm guidelines on how to admit people for surgery.

### **D) No Diagnosis or Treatment Plan Communicated to Consumer**

"I was taken to the emergency department at the hospital and was admitted there, and I just seemed to stay there, day after day and I wasn't told anything...I didn't see a doctor. No-one said, 'Look, this is what is wrong, this is what we are going to do and this is how we are going to do it.' So complete failure to communicate."

### **CONSUMER SOLUTIONS**

A bit part of this consumer's problem was not being told any diagnostic or treatment plan. She would like to have been informed about the treating doctor's thoughts on, "This is what we think is wrong, this is what we are going to do, and this is how long we will need you to be here. Any questions."

This consumer suggested that an admission leaflet be produced which let consumers know how the hospital is run... "You know, there are certain basic standard procedures...Is your case going to be managed by a consultant...they will see you maybe twice a week. If there are any problems during the night the house surgeon will be on call to answer any questions...that sort of thing. They should be letting patients know actually what is going to happen when they are in hospital..."

### **E) Inefficient Use of Resources**

The system issue raised by this consumer was that after 20 years a diagnosis for pain was finally reached via a team of neuro radiologists and neurosurgeons using a series of Magnetic Resonance Images. When the consumer experienced another episode of collapse, black out and paralysis, post diagnosis in 2001, it appeared another teaching hospital was going to start the diagnostic process all over again...In the consumer's words,

"And I thought it just seems to be ridiculous that I should start the whole process again from the beginning as if I had never had a diagnosis...which is what they wanted to do. 'Cos what I have discovered since is that the Pain Clinic is not part of the hospital, it is a private clinic, they (just) use facilities at the hospital. So there was no liaison or communication between the two, which is just nuts...but that's what happened."

So I said, "well I don't want to do this." I want to go to the team that originally diagnosed me and follow through with these guys. I thought it made a lot more sense."

This case raises the issue of efficient use of resources. Had the consumer been a passive and compliant one, it appears that the hospital system would have undertaken another series of MRI

scans, when a diagnosis had already been made. The efficiency case also involves communication as an issue.

### **CONSUMER SOLUTIONS**

This case highlights the importance of logistics and communication between consumers and treating teams, and the cost to the consumer and the community when it fails to be effective communication. It appears from what the carer relays that this simple solution had not been considered by the treating team.

#### **Discussion:**

The concerns also introduce questions surrounding health care rationing. Ongoing community input and consultation is important to ensure that the ethical issues surrounding questions of healthcare rationing are open, transparent and do not end up being determined by a market driven restriction to health access.

### **Chapter 9**

#### **THE PUBLIC/PRIVATE DIVIDE**

100 out of 169 (59.1%) individual advocacy cases brought to the Health Consumers' Council in the 18 months between January 2000 and June 2001 were related to public health service providers, including public mental health advocacy cases. 69 of 169 (40.8%) individual advocacy cases were related to private health service providers (private hospitals, general practitioners, private mental health services, private dental services and any other private health services).

Of the 14 interviews conducted in the qualitative component of the research, three interview participants introduced issues relating to the public / private divide of their own accord. Two of these people had private health insurance, but were admitted through emergency departments of the large teaching hospitals. They each raise noteworthy issues about the way the public/private split in the hospital system operated for them.

#### **A) Treatment as a 'public patient.'**

This interviewee introduced the issue of treatment and discrimination as she attempted to find reasons for why the attention she received through an emergency department was inadequate. This consumer raised issues of class prejudices and consequent discrimination.

"I thought they were discriminating on the grounds of public patients appearing in an emergency department. I had private health insurance but nobody ever asked about that. You know...there is an assumption that they are all public patients (at that hospital). I thought they were discriminating on the grounds of age, I thought they were discriminating on the grounds of, you know public patients appearing in an emergency department."

Interestingly, this same consumer is involved in a volunteer group who invited an anaesthetist to speak. The visiting anaesthetist revealing the following attitudes.

'well with private patients of course you do that, (pre operative consults) because you get paid. You don't get paid for a pre-operative visit in the public health system, and besides...you know...there is just a world of difference between private and public patients. You make the effort for private patients. Public patients they are rude, they never say thank you...private patients are you know outgoing ...intelligent ...educated...'

### **CONSUMER SOLUTIONS:**

The interviewer asked the consumer how they thought such prejudices might begin to be broken down.

"Well I think you have to look at it on a microcosmic level...like say look at (hospital A) for a starter. And have workshops on breaking down the (class) barriers."

This consumer also suggested **role plays** as a way of educating health professionals about 'walking in another persons shoes'....about what it feels like to be a consumer being treated by a health service provider when all is not going well and the consumer feels powerless to influence the dynamic of the communication and consequent treatment.

"I have this fantasy of a workshop where you have a whole lot of doctors and you have a whole lot of consumers who have had bad experiences and they have to role-play (opposite parts)."

### **B) Private Provider Accountability to Hospital**

The second consumer who raised the public / private issue was admitted as a private patient through the emergency department of a public hospital, and had a public surgeon operate on them. The consumer and carer experiences in this case echoed the experiences of other health consumers attending public hospitals as private patients, who perceive that their private health status seemingly poses obstacles to having the public hospital staff intervene on behalf of the patients' best interest when the private specialist is not available. This interviewee was of the opinion that public hospital staff do not want to become involved in difficult medical cases 'under' private specialists.

"I was private all the way through. Even at the government hospital, where I went in as an emergency, I went in as private. That is one of the problems too, like I've seen in the paper recently...if you are a public patient you are better off. That is what it seems to us. If you are a private patient, nobody wants to have a bar of you in the hospital. It is all up to the surgeon...and like...you just can't do anything...You are better off to go in as a public patient, because nobody...the surgeon didn't even want to come in, even though I was a private patient. (The doctor) wouldn't (attend). And nobody knows what to do, because nobody wants to tread on anyone's toes, but then because you are a private patient...(the private specialist) doesn't seem to be accountable to the hospital. He is his own realm, you know. He is not accountable to the sort of public...entity.... And it wasn't as if the doctor wasn't being told, because he was being told."

### **CONSUMER SOLUTIONS**

"I think there also should have been a bit more accountability on behalf of the hospital."

"I do feel that if the hospital is going to allow these doctors to work, that there has to be some sort of accountability (on the part of) the hospital."

The second solution the consumer identified was to have knowledge of the processes available within the hospital to seek redress.

"And you need someone to be able to guide you into saying 'Listen, this is what you can do.' But there was nobody, you know, there there was nobody there to say, alright you can do this."

### **Discussion:**

These two reports indicate that consumers feel that their health insurance status affected the quality of treatment received. It is a community expectation that all citizens are entitled to quality health care and that this ought not be determined by one's health insurance status.

Medical and legal ethicist Paul Komesaroff points out that if financial considerations become dominant, "the physician becomes the agent of the hospital or the system rather than of the patient." He goes on to say that the practitioner's "primary obligation to act on behalf of the patient is displaced in favour of conformity to a complex system of economic incentives and disincentives. The scope for interested compassionate care is greatly contracted." (cited in

Nason and Kerin, 2002.)

The consumer reports above indicate that consumers feel this scenario is already a reality in some instances.

## **Chapter 10**

### **CONSUMER CONCERN FOR PUBLIC SAFETY AND LACKS IN THE REGULATORY BODIES**

This loss of faith mentioned in chapter three is further exacerbated when the consumer knows that their experiences at the hands of service providers have not been used to help improve the system for other consumers.

The following case studies highlight examples of Western Australian health consumers who have attended health professionals, lodged complaints regarding the lack of care received and their complaint has not effected any changes in the system. In some instances the regulatory bodies and the second opinion service providers continue, in the eyes of injured consumers, to fail to protect the public.

#### **A) Consumer concern for public safety issues.**

"It would be very frustrating for me to find out that he is still working ...that I cannot do anything to stop him...I mean he may do this to other people... when I think that he is working and if I find out that he is working...gee...I don't know, I would feel terrible. What can I do? I can't do anything by myself. I'm trying to talk to people, I'm trying to, as much as I can, I'm trying to let everyone know what happened to me so they can stop this man doing it. And maybe there might be some more people who are not qualified and not doing appropriate. You know we are talking about health problems, you know this is something that affects people for the rest of their lives. This is not carpentry or, this is something that cannot be repaired. This is human beings. This is us."

#### **B) Concerns About Regulatory Bodies**

"The Medical Board knew of this man I found out all about his history after my surgery. The Medical Board needs to stop sitting on their hands and do something constructive to help the consumer, not protect the doctors giving them the benefit of the doubt."

"...because if you don't because if you fail to acknowledge (that a problem occurred), then you don't treat the problem. And umm that was (what happened with one particular regulatory body). In their refusal to acknowledge (the problem) they are leaving everyone else at risk, the same risk, and exactly the same risk."

#### **CONSUMER SOLUTIONS**

More stringent credentialing and greater publicity of 'problem service providers.'

#### **Discussion:**

There was a strong sense from the consumers who were interviewed that the current overseeing bodies, such as the Medical Board and the Office of Health Review, did more to protect the health service provider than the consumer. The proposed Administrative Appeals Tribunal may go some way to offering a more independent regulatory forum of appeal.

## **Chapter 11**

### **PURSUIT OF JUSTICE**

The Health Consumers' Council is of the view that consumers who seek redress for injustices they

have experienced in the health system are driven by a conviction that the incident that occurred ought not to have happened or could have been dealt with more fairly.

This pursuit of justice is something the aggrieved consumers and carers cannot just put aside.

Seeking redress may be in the form of an acknowledgement that things were not done as well as they might have been, an apology and some genuine effort to minimise the chances of similar incidents occurring again. (A willingness to learn from mistakes.) Redress may also be in the form of financial compensation.

The case giving rise to this chapter involved a carer who seeks the chance to access an organ transplant for their partner. There is an expectation that the health system will allow some flexibility to accommodate the individual needs of consumers, and not just 'close the door' on the opportunity for life saving treatment. It seems age is a factor in 'the door being closed' in this case, however the consumer has also identified many other factors which have contributed to her grievances with the system and the way she and her partner have been dealt with.

#### Consumer Report 1:

The carer interviewed had been seeking treatment for her partner for many years. Her efforts to have her partner treated included travelling to Adelaide twice to seek a second organ transplant panel's opinion on the eligibility of the consumer receiving a transplant. This was necessary as the Western Australian transplant unit refused to even wait list her partner and Western Australia did not have the ability to provide an independent second opinion.

"In the end the Health Department agreed to send my partner to Adelaide for an independent assessment...The only problem is that once they put you on the waiting list you have to go and live in Adelaide. Because they give you a tag to wear, with a beeper. And when they beep you have to come straight away to the hospital.

Interviewer: So they decided that they could do (the transplant?)

"Yes. They said that."

Interviewer: And you couldn't get that (decision) here in WA?

"No."

Interviewer: But you have to go and live there?

"Yes. And again you see the dilemma is...my partner is now 69, and age is getting against him. The older you are the, the less chance you have to sur...of coping with it better."

Interviewer: And when do you think he should have been put on a list then. How long ago?

"Well, if he had this problem...he should have been on the list much earlier, when he was younger, you see... he should have been considered when he was younger I suppose. Oh probably in 1985...or maybe later, maybe a bit later Yes."

"The hospital was reluctant to have our (private) specialist come with us...yes... Well I feel they failed us because...they sort of closed the door. You know if there are two conflicting opinions, we felt there should be more interactions between the hospital and my husband, and they just wouldn't budge. They wouldn't consider him. They wouldn't (even) test him. They just said no. Flatly no.

It is no good us going (to the transplant panel) without a specialist (advocating for us).

Because I am not a medical person...(our specialist) could present the case on our behalf. But they never wanted (out private specialist there) We could come. But not him"

Interviewer: So people are not allowed to bring a doctor with them at all?

"Well, I don't know if othe people are allowed or not, but we were not encouraged to bring him. ...That I think, was on two occasions"

Interviewer: You have been before the panel twice?

"No we haven't. Because there is no point going by ourselves, you see."

The consumer has a private specialist who has carried out testing and who believes the patient is able to be transplanted. The Transplant Panel reportedly will not allow the consumers private specialist to attend the Panel meetings.

#### **CONSUMER SOLUTIONS**

- Some doctors or a panel who are independent of the Transplant Unit in WA, involved in eligibility assessment.
- Along similar lines, consumers should be able to bring own private doctor, as a patient advocate, to the Panel meetings.
- Increased efforts to improve organ donation rates in the public domain.

#### **Discussion:**

This particular case raises issues relating to health rationing as well as the acute shortage of organ donations for transplantation and the way in which the system is set up to exclude certain doctors (those acting as patient advocates) from the decision making process.

On the issue of health rationing, Nason and Kerin (2002) point out, it currently exists, to some degree, behind closed doors and whilst this situation remains, Alan Henderson, director of intensive care at a Brisbane's hospital believes...

"there is a danger of rationing being irrational as the ethical and justice questions are resolved not with community input but by the "secret societies" of politicians, bureaucrats and drug companies that run healthcare in Australia today."

Henderson is quoted in Nason and Kerin's article as saying 'We need an ethical framework and if we don't have community involvement in deciding that ethical framework we are likely to wind up with a market-determined way of restricting health access. In that scenario it will be the poor, the elderly, the disabled and the disadvantaged who will be cast adrift.' "

#### **Chapter 12**

#### **QUALITATIVE DATA SUMMARY**

The common themes coming through in this summary of the 14 interviewees' suggested solutions are,

- The need for improved communication and treatment.
- Requests for greater independence of investigating and accreditation bodies of the practitioners and the system. (Consumer focused investigating bodies.)
- Increased privacy and confidentiality.

- Openness and honesty with errors.
- Greater flexibility within given systems to accommodate extenuating circumstances.
- Independent accreditation and overseeing of allied health practitioners such as counsellors, chiropractors.
- Lateral thinking from practitioners with health resources.

The statistical findings on the 169 advocacy cases over 18 months identified that treatment and communication issues formed 62.4% (almost two thirds) of total complaints. The qualitative component of the research also reflects similar consumer concerns. All 14 interviewees expressed that the problems they had encountered within the health system were related to, and exacerbated by, complexities arising from problems in communication.

The interviewees often had practical suggestions on how communication and treatment might be improved. These included the recommendation of;

- Workshops, at the local level, to help breakdown the private/public patient divide.
- Role-plays with patients in the service provider role and doctors as the upset and disempowered consumers. (Professional actors could also be involved.)
- The production of a 'What to expect on admission' leaflet by hospitals.
- Firmly written down guidelines on admission processes for doctors to follow.
- Providers who are more actively engaged in advocating for patients.
- Service providers who are able to more effectively empathise and 'walk in the patients' shoes.'

The identification of issues surrounding communication and treatment is further discussed in chapter 2 and is the most evident theme running through the consumer interviews.

## **PART 2 – QUANTITATIVE RESEARCH FINDINGS**

### **Method**

The statistical component of the research was conducted through manual handling of 169 individual advocacy cases which had been undertaken by Health Consumers' Council Advocates between January 2000 and June 2001. It involved the extraction of information such as

- Complaint Category,
- Service provider type,
- Gender of consumer and provider (where applicable)
- Postcode

in order to provide statistical data on such determinants.

Service provider types were broken down to give the following categories:

1. TOTAL Complaints within each Complaint Category.
2. Public Hospitals – Metropolitan and Rural (excluding mental health settings) **34.9%** total complaints
3. Public Mental Health Services (Metropolitan and Rural). **19.5%** total complaints
4. Public Health Services: Other **4.7%** total complaints
5. TOTAL Complaints relating to Public Health Services (including Mental Health)**59.1%** total complaints

- 5. Private Hospital. **4.1%** total complaints
- 6. Private Mental Health (private Psychiatric hospital and private psychiatrist. **3.6%** total complaints
- 7. General Practitioners. **16.5%** total complaints
- 8. Private Physicians. **3.6%** total complaints
- 9. Private Surgeons. **7.1%** total complaints
- 10. Private health services: Other. **5.9%** total complaints
- 11. TOTAL Complaints relating to Private Health Services. **40.8%** total complaints
- 12. TOTAL Complaints relating to Mental Health Settings: Private and public. **23.1%** total complaints

This enabled a numerical comparison to be conducted between Public and Private service provision as well as the complaint type within each service provider type.

Of the 169 advocacy cases under in the 18 month period under audit, there were contacts to the Council by

- 31 rural consumers,
- 129 metropolitan consumers and
- 9 cases where the place of residence of the individuals seeking advocacy assistance from the Health Consumers' Council is unknown.

## **Chapter 13**

### **STATISTICAL DATA SUMMARY**

#### **TOTAL COMPLAINTS WITHIN EACH COMPLAINT CATEGORY** **(across all service provider types)**

169 individual advocacy cases brought to the Health Consumers' Council in 18 months related to metropolitan and rural public and private health services provided to Western Australians. This was a total of 255 complaints (many cases involved multiple complaints) pertaining to the 169 individual advocacy cases.

#### **Total Complaints surrounding Treatment.**

- 40.8% of complaints from the 169 advocacy cases brought to the Council included issues to do with clinical treatment. 22% cases included the sub category 'inadequate treatment.'

#### **Total Complaints surrounding Communication.**

- Communication was the second most prevalent complaint category throughout the statistical research, with 21.6% of the 255 complaints relating to communication issues. The subcategory 'Misinformation or failure in communication' received 14.1% of all complaints.

**Treatment and communication issues therefore formed 62.4% (almost two thirds) of total complaints. It would be reasonable to conclude from this that these are two areas worthy of attention for improvements in safety and quality health care.** The qualitative component of this research paper further highlights the importance of communication for optimum treatment and the inextricable links between the two aspects of health service provision.

A breakdown of other Complaint Categories is as follows:

- access received 7% of total complaints.
- costs – 5.1%.
- professional conduct - 4.7%.
- discharge processes – 3.1%.
- rights – 2.7%.
- records: unavailable on date of service – 2.7%.
- consent – 2.7%.
- administration – 2%.
- Admission – 0.8%.
- Other- 5.9%

## **PUBLIC HEALTH SERVICE PROVIDERS**

### **TOTAL Complaints relating to Public Health Services (including Mental Health Services)**

**100 out of 169 (59.1%) individual advocacy cases brought to the Health Consumers' Council in 18 months related to public health services.** These services include public hospitals (rural and metropolitan) public mental health services, Patient Assisted Travel Scheme, Disability Services Commission services, public dental services and public psychological services.

Most complaints relating public health services were surrounding;

- treatment issues (37%)
- communication issues (19.9%). **Treatment and communication made up 56.9% of complaints.**
- access (10%)
- professional conduct (5.7%).
- Discharge process (5.7%).

Within these three categories, the main sub categories featuring in consumers' grievances about the public health services were inadequate treatment (22.1%), negligent treatment (6.4%), misinformation or failure in communication (10%) and delay in admission or treatment (3.6%) and inadequate or no service (4.3%). Professional conduct also registered 5.7% of complaints relating to public health services. Discharge process also featured as an aspect of consumer grievances in 5.7% complaints.

The 'other' category, with 6.3% of total complaints relating to public health services included bodies such as Patient Assisted Travel Scheme, Disability Services Commission, Medicare, public dental services and government psychology services.

## **PRIVATE HEALTH SERVICE PROVIDERS**

**TOTAL Private Health Services**

69 of 169 (40.8%) individual advocacy cases brought to the Health Consumers' Council in 18 months related to private health services. These include private hospitals, general practitioners, private mental health services, private dental services and any other private health services providers not fitting into the aforementioned categories.

Advocacy cases brought to the Health Consumers' Council relating to private health service providers highlight:

- treatment (44.8%)
- communication (23.3%) as areas worthy of attention.

Within these categories, the sub categories of 'inadequate treatment' (24.2%) and 'misinformation or failure in communication' (17.5%) formed the bulk of the complaints.

This finding is congruent with other health service provider categories who also had the majority of complaints around treatment and communication issues. **In the private sector, treatment and communication issues made up 68.1% of total complaints.**

- 5 complaints related to unprofessional conduct (4.2%) and
- 3 complaints (4.2%) related to rights (less favourable treatment on grounds of some form of discrimination.)

8% of complaints related to 'Other' private health services. Of the two cases involving dental services inadequate treatment and costs ('unsatisfactory billing practices' and 'amount charged') occurred as a component of both complaints.

**TABLE SUMMARY OF STATISTICAL FINDINGS (SERVICE PROVIDER TYPE AND COMPLAINT CATEGORY)**

TOTAL Complaints in each Complaint Category	Public Hospitals: Metro & Rural	TOTAL Public Mental Health Services: Metro & Rural	Public Health Services:Other	TOTAL Public Health Services: Including Mental Health	Private Hospitals	Private Mental Health Setting	General Practitioners	Private Phys...
<b>Treatment</b>	40.8	39.5	44	28.6	37	26.5	43.7	52.3
<b>Communication</b>	21.6	21	18.6	14.2	19.9	33.2	37.5	19.4
<b>Treatment/Communication Combined</b>	62.4	60.5	62.6	42.8	56.9	59.7	81.2	71.7
<b>Professional Conduct</b>	4.7	7	4.6	0	5.7	6.6	6.2	4.8

<b>Rights</b>	2.7	4.6	0	0	2.1	0	6.2	4.9
<b>Access</b>	7	4.6	13.9	28.6	10	0	0	4.8
<b>Costs</b>	5.1	0	0	14.2	1.4	13.3	6.2	4.8
<b>Administration</b>	2	3.5	2.3	0	2.9	0	0	2.4
<b>Diagnostic Services</b>	0.4	0	0	0	0	0	0	0
<b>Hygiene</b>	0.4	0	0	0	0	6.6	0	0
<b>Records</b>	2.7	4.6	0	0	3.6	0	0	4.8
<b>Assault</b>	0	0	0	0	0	0	0	0
<b>Consent</b>	2.7	1.2	0	0	1.2	6.6	0	0
<b>Admission Process</b>	0.8	1.2	2.3	0	1.4	0	0	0
<b>Discharge Process</b>	3.1	5.8	7	0	5.7	0	0	0
<b>Other</b>	5.9	7	11.6	14.3	6.3	13.3	0	0

## **GENDER**

### **Gender of Consumers**

Of the 169 advocacy cases under audit, 68% of the consumers were female (115 individuals), 28% were male (48 individuals) and in 3.65% (6 cases) the people seeking advocacy were a couple (parents) or gender is unknown.

### **Gender of Service Provider**

In many instances the gender of the service provider was not known or not relevant eg. was a hospital. However, where it was possible to ascertain the gender of the service provider (64 cases), 17 were female and 47 were male.

In 105 cases it was not possible to say i.e. the provider was a hospital and the category is not applicable or unknown.

## **SOCIO ECONOMIC STATUS OF ADVOCACY CONTACTS WITH THE COUNCIL**

From the 169 individual advocacy files it was possible to obtain 146 postcodes which gave the residential locality of the individuals who had sought advocacy assistance from the Health Consumers' Council in the 18 months between January 2000 and June 2001. These included:

- 40 rural consumers (23.7%);
- 106 metropolitan consumers (62.7%) and

- 23 unknown postcodes (13.6%).

Socio economic decile ranking produced by the Department of Education<sup>i</sup> were applied to these postcodes. This enabled a fairly crude socio economic analysis to be conducted on 85.8% of the advocacy cases brought to the Council in the period under audit.

86 of 146 postcodes had a ranking of 6-10 inclusive. This translates to 59% of cases falling into the 'lower' half of the population in terms of socio economic disadvantage.

60 of the 146 postcodes had a ranking of 1-5 inclusive. This represented 41% of individuals seeking advocacy fell into socio economic decile ranking in the 'upper' half of the population in terms of socio economic advantage.

Following is a breakdown of these findings,

Decile	1	2	3	4	5	6	7	8	9	10	
Raw No	18	13	11	10	8	27	16	12	27	4	
% of total	12.3	8.9	7.5	6.8	5.5	18.5	11.0	8.2	18.5	2.7	
%age advocacy contacts from individuals residing in upper 50% socioeconomic decile rankings	41					%age of advocacy contacts from individuals residing in lower 50% socioeconomic rankings					59

### **Discussion:**

The figures here appear are reasonably well spread, with a slightly higher (approximately a 60:40 ratio) representation of people from the 'less advantaged' half of the population. Overall, one could conclude from these statistics that people from all walks of life encounter difficulties within the health system which they find they prefer assistance from a third party to help resolve.

When the postcode data analysis was proposed, it was anticipated that more people in the lower decile rankings contact the Council for advocacy assistance. This expectation, however, is only marginally true.

It may be worth noting here that the breakdown of contacts to the Council for advocacy assistance within the 18 month period of audit was 59.1% relating to public health services, including public mental health services, and 40.8% relating to private health service providers.

## **Chapter 14**

## **CONCLUSION**

This consumer focused research has unequivocally shown that the link between communication and treatment is fundamental to good quality health care.

The 14 interviews have clearly drawn connections between problems with communication which frequently lead to, or exacerbate treatment related issues. Individually, these failures in communication may be due to a failure to warn of risks or options, provider held assumptions which affect the quality of the treatment received, poor quality attention, failure to disclose an adverse event, dismissal of consumer concerns, and an inability to apologise or acknowledge consumer distress.

The statistical component (Part Two) similarly reveals high rates (between 60% and 81%) of complaints relate to communication and treatment across public and private service provider types.

On a systemic level, the 'system's' failure to respond to consumers when legitimate grievances arise exacerbates a loss of faith in the overseers of the health professionals. Individuals in the system who fail to support the consumer are then seen as apologists for a system, which in the consumer's experience, caused them additional physical or emotional harm.

The manner in which health professionals communicate with consumers, in regard to adverse events or more generally, can cause further affront and leads to a loss of faith in practitioners and the system. Consumers are likely to feel that there is little justice for them within the current system.

Good communication forms the basis of relationship and rapport. Health care, at its best, requires a consumer-provider relationship based on reciprocal respect. Practitioners are able to restore the faith of aggrieved consumers through engaging with consumers in a respectful, humane, compassionate and caring manner. Health consumers value effective communication, treatment and diagnosis which includes respect, honesty, information and effort coupled with care and humility from health service providers.

The socio-economic data reveals that Western Australians from all walks of life seek advocacy assistance to help them to move a difficult situation forward. 41% of contacts with advocates at the Health Consumers' Council came from the upper 50% of the socially 'advantaged' population. This is indicative of the fact that difficulty in negotiating problems within the health system is universal across all sectors of our society.

## **RECOMMENDATIONS**

This consumer focused research recommends that:

- Health service providers and consumers in Western Australia would benefit from recognising and acknowledging the importance of good communication to optimum health service provision.
- Individual practitioners need to take responsibility for their own standards of communication with consumers to whom they owe a professional duty.
- Structurally, health services need to build in the capacity for clinicians and practitioners to spend extra time and attention providing information within professional, respectful relationships with consumers.
- Endorsement by health services and practitioners of the principle of Open Disclosure in the event of an adverse outcome and the need to provide redress where appropriate.

## **REFERENCES**

Blackwell, S. (2001 December) 'Citizens' Juries'. Paper presented at Searching Our Futures: Consulting Citizens by the Citizens and Civics Unit, Policy Office of the Office of the Premier and Cabinet, Curtin University, Perth, WA.

Consumers' International. (1996) The Rights of Patients. London: Global Policy and Campaigns Unit, Consumer International.

Davis, A. (1998) Case Studies In C. Kerr & R.Taylor (Eds.), Handbook of Public Health Methods, (pp496-503) McGraw Hill Book Company, Sydney, NSW.

Federal Privacy Commission (2001) Guidelines on Privacy in the Private Health Sector, (online) Available [www.privacy.gov.au/publications/hg\\_01.html](http://www.privacy.gov.au/publications/hg_01.html)

Ford, G., (2001). 'Patient Satisfaction Surveys in Australian Public Hospitals', Health Issues, Vol 68, Sept.

Health Administrative Review Committee, 2001, Report of the Health Administrative Review Committee, Perth.

Health Consumers' Council (2001) Contract Advocacy Research Project. Perth WA: Author

Health Consumers' Council (2002) Advocacy and Complaints (online). Available [www.hcc-wa.global.net.au/pages/advocacy.html](http://www.hcc-wa.global.net.au/pages/advocacy.html)

Hopkins H.& Brady M., 2001, Statement for Consumer and Community Participation in Health and Medical Research, Consumers' Health Forum, Sydney.

Hutchison, A., (2002) Personal communications. Available E-,mail: Alistair.HUTCHISON@eddept.wa.edu.au

Kerslake, D., (2002) 'Finding the Balance in Complaints Handling,' OPA (Office of the Public Advocate) News, July/August 2002, Perth WA.

Lawrence, D., Holman D., & Jablensky A. (2001). Duty to Care – Preventable physical Illness in People with Mental Illness University of Western Australia, Perth.

Nason D. & Kerin J., 2002, May 18-19) Roulette in Triage, The Weekend Australian, p.25.

NHMRC Council, 1999, National Statement on Ethical Conduct in Research Involving Humans, Commonwealth of Australia,

Canberra.

NHMRC, 2001, The Human Research Handbook, Commonwealth of Australia, Canberra.

Patton, M. (1999) Qualitative Evaluation and Research Methods. Sage, Newbury Park, CA

The Public Interest Advocacy Centre and the Australian Council for Safety and Quality in Health Care, (2002). When things go wrong – an open approach to adverse events. (Issues paper), Sydney, NSW: Author.

Wadsworth Y. 1997, Do It Yourself Research, Allen and Unwin, Sydney.

Williams, B., Coyle, J. & Healy, D., (1998). 'The meaning of patient satisfaction: an explanation of high reported levels,' Social Science and Medicine, Vol. 47, No. 9, pp1351-1359.



Health Consumers' Council  
Unit 13/14 Wellington Fair  
4 Lord Street Perth WA 6000

## **IN OUR OWN WORDS: Western Australian Health Consumers' Speak on their experiences in the Health System.**

"I cannot just let go and say...OKthis happened...somebody says, "Well you lost a leg" but you don't know how you lost it. You can't just go on with your life when you don't really know what happened. You cannot just get on with your life because you can't get it back now. It's not that easy. I'm just looking for a cause for what really happened there."

### **Advocacy Research Project**

**Prepared by Andrea Callaghan**

**These papers are written by Mental Health Consumer Consultants. The writers are not medically trained but people with the lived experience of mental illness.**

Funded by the Department of Health (WA)

