



Open Disclosure: A Review of the Literature

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Executive summary

Scope

In 2008 industry partners from the health, insurance and legal industries in Western Australia commissioned Edith Cowan University to conduct this literature review to understand how open disclosure is defined in health systems. The full list of industry partners is listed in Appendix A.

This paper was funded by a grant received from the Val Lishman Health Research Foundation and aimed to identify:

- open disclosure policies in Australia, the United States, United Kingdom and Canada and how they are defined;
- the key success factors of open disclosure policies for professionals, patients and their families;
- the barriers to open disclosure, and
- recommendations for further research.

Background

In April 2008 the Health Ministers in Australia agreed to work towards implementing the National Open Disclosure Standard in all health care facilities. Open disclosure is a facet of ethical communication and part of a process to improve the quality of health care. The policy exists in countries such as Canada, the United Kingdom and the United States, but under different names. Representatives from different industries in Western Australia who are impacted by this policy have joined together to investigate the issues around its implementation.

Findings

The definition of open disclosure in the different countries is not exactly the same, but most emphasise open and honest communication with patients and their families after an adverse incident. Studies conclude that open disclosure has economic advantages and that professionals, patients and families support it. Researchers argue that for open disclosure to be effective, open communication should start at the beginning of a health care episode and continue throughout. In other words, professionals should always communicate in an open and ethical manner.

Existing research is generally based on anecdotal evidence, speculation, and the feeling that open disclosure “makes sense”. This review reveals that there is a lack of empirical evidence, especially quantitative evidence, regarding:

- the factors required for successful open disclosure;
- whether using open disclosure brings about any measurable advantages for those who its supporters say it will bring benefits;
- the barriers to the use of open disclosure; and
- the needs of patients, families, professionals and institutions when involved in open disclosure.

Recommendations for further research

The following research questions that require further investigation have been identified:

1. Is organisational culture a barrier to the implementation of open disclosure?
2. How does an organisational culture have to change in order to adopt open disclosure?
3. How can these changes in organisational culture be facilitated?
4. What factors influence professional communication around adverse incidents in institutions?
5. What factors need to be present for open disclosure to optimally satisfy the needs of all involved with the process?
6. What training do professionals need to ensure they feel and are competent to undertake open disclosure proceedings?
7. Does open disclosure bring about actual financial savings?
8. What is the impact on professionals who engage in open disclosure proceedings?
9. What support do professionals require in order to facilitate the open disclosure process?

1 Open disclosure policies

1.1 Background

In April 2008 Australian Health Ministers agreed to work towards implementing the National Open Disclosure Standard in all health care facilities in the country (Australian Council for Safety and Quality in Health Care, 2008). Open disclosure as a concept has been around in Australia much longer and can probably be traced back to the ongoing attempts to improve the quality in health care that manifested in Western Australia (WA) with the passing of the *Health Services (Quality Improvement) Act* 1994. More recently the Open Disclosure Standard (Standard) was adopted by the Australian Council for Safety and Quality in Health Care (2003a) and the concept has been adopted by professional medical organisations in Australia for some time (Bolsin, Solly, & Patrick, 2003; Peterson, 2003; Pitman, 2006). Similar policies, but with different names, can be found in other health systems internationally.

1.2 Defining and describing open disclosure

The first system to adopt a policy of openness in dealing with adverse incidents was the United States (US) Veteran Affairs medical system that adopted it as a risk management process (Department of Veterans Affairs, 2008; Kraman & Hamm, 1999). Other health systems in the US followed with the Joint Commission on the Accreditation of Health Care Organizations (JCAHO; Joint Commission on Accreditation of Health Care Organizations, 2001) and the American Hospital Association adopting a policy for the disclosure of adverse events (Lamb, 2004). The National Health Service (NHS) in the United Kingdom (UK) adopted a policy to implement a “duty of candour” (Chief Medical Officer, 2003) after many inquiries into the errors within the NHS (Walshe & Higgins, 2002). Canada likewise adopted a set of Disclosure Guidelines in March 2008 (Disclosure Working Group, 2008).

All these policies share common features but as Table 1 shows the nomenclature differs from system to system. For ease of communication I will refer to all these policies as open disclosure policies unless I want to highlight an aspect that is specific to a particular policy.

Table 1: Nomenclature used in different policies

Nomenclature	Reference
USA	
Full-disclosure	Hoy (2006, p. 412)
Structured and <i>compassionate error-disclosure</i>	
Proactive full disclosure	Kraman and Hamm (1999, pp. 963-964)
UK	
Duty of candour	Chief Medical Officer (2003, p. 18)
Honest disclosure	Lamb (2004)
Canada	
Disclosure of harmful errors	Levinson and Gallagher (2007)

Another feature of the different policies is that the definitions used in them vary (see Table 2).

Table 2: Definitions of open disclosure

Definition	Reference
Open disclosure is the open discussion of incidents that result in harm to a patient while receiving health care	Australian Council for Safety and Quality in Health Care (2003a, p. 1)

Definition	Reference
Patients and, when appropriate, their families are informed about the outcomes of care, including unanticipated outcomes	Joint Commission on Accreditation of Health Care Organizations (2001, pp. 13-14)
Duty of candour requiring clinicians and health service managers to inform patients about actions which have resulted in harm	Chief Medical Officer (2003, p. 18)
The process by which an adverse event is communicated to the patient by health care providers	Disclosure Working Group (2008, p. 8)

These definitions all emphasise communication with patients and their families after an adverse incident, with variations in each beyond that theme. Commentators' interpretation of these definitions is that the relevant communication must be open and honest (e.g., Fallowfield & Jenkins, 2004; Joint Commission on Accreditation of Health Care Organizations, 2001; Koh & Alcock, 2007; Kraman & Hamm, 1999; Lamb, 2004; Levinson & Gallagher, 2007; Wei, 2007).

The elements of open disclosure found in the Standard that was published by the Australian Council for Safety and Quality in Health Care (2003a, see Table 3), are similar to the elements identified by the Australian Health Ministers Advisory Council (2003), except that the latter refers to an apology as well.

Table 3: Elements included in the Australian Open Disclosure Standard Australian Health Ministers Advisory Council (2003, p. p. 11)

<ul style="list-style-type: none"> • Acknowledge that an adverse event has occurred • Acknowledge that the patient is unhappy with the outcome
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-
- Express regret for what has occurred
 - Provide *known* clinical facts and discuss ongoing care (including any side effects to look out for)
 - Indicate that an investigation is being, or will be undertaken to determine what happened and prevent such an adverse event happening again
 - Agree to provide feedback information from the investigation when available
 - Provide contact details of a person or persons within the health care organisation whom the patient can contact to discuss on-going care
-

Most of the elements set out in Table 3 are similar to those found in the policies in other systems (Chief Medical Officer, 2003; Disclosure Working Group, 2008; Joint Commission on Accreditation of Health Care Organizations, 2001; Kraman & Hamm, 1999). However, some policies identify more elements. For instance, the manual of the Department of Veterans Affairs (1998, cited in Kraman & Hamm, 1999) adds elements about interacting with patients and their families, including advising them about their legal rights (see Table 4).

Table 4: Additional Elements of Open Disclosure the US Department of Veteran Affairs Manual (Veterans Health Administration, 2008)

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- The patient or family are informed of the event as soon as possible, and of further medical assistance that will be provided to the patient
 - Counsel will advise the patient regarding their legal rights
 - Patients are advised about the available remedies for the unanticipated outcome, and in circumstances involving malpractice or injury the Department of Veteran Affairs may advise patients to make a claim against the government
-

The policy in the UK, on the other hand additionally deals with professionals' legal and ethical indemnity (see Table 5).

Table 5: Additional elements found in the UK (Chief Medical Officer, 2003)

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- There is an exemption from disciplinary action for those professionals reporting adverse events or medical errors, except where there is a criminal offence
 - Legal privilege is provided for reports and information identifying adverse events except for information that is not recorded by the health care centre
-

1.3 Goals of implementing open disclosure

The perceptions of authors' whose works were reviewed regarding the purpose of open disclosure vary as a function of what their role is and the list of goals is long (see Table 6).

The most frequently cited goal of an organisation in implementing open disclosure is to reduce medical liability payments. They believe that by honestly notifying patients of substandard care, offering timely comprehensive help in filing claims diminishes the anger and the desire for revenge on the patient's behalf that often motivates litigation (see, e.g., Kraman & Hamm, 1999). Kraman and Hamm provides anecdotal evidence that suggests that where the adverse event was disclosed plaintiff's attorneys are often willing to negotiate a settlement based on calculable monetary losses instead of on the potential for hefty rulings that contain a punitive aspect.

Despite these economic advantages, the authors strongly advocate for the "goodwill and the *maintenance* of the caregiver role" (Kraman & Hamm, 1999, p. 966), as the main goal. This notion to restore the doctor-patient relationship is further enhanced by the wording used throughout the explanation of the economic advantages, for example, "unanticipated financial benefits" (Kraman & Hamm, 1999, p. 964).

Table 6: Functions of open disclosure

Functions	Reference
Lesser likelihood of litigation	Fallowfield and Jenkins (2004)
Feeling relief from guilt	Fallowfield and Jenkins (2004) Field and Copp (1999)
Promoting trust	Fallowfield and Jenkins (2004)
Strengthening doctor-patient relationships	Fallowfield and Jenkins (2004) Field and Copp (1999)
Provide an environment where patients and their support person receive the information they need to understand what happened	Australian Council for Safety and Quality in Health Care (2003a) Iedema et al. (2008)
Ethically, patients require information regarding errors, so as to make informed decisions regarding their subsequent treatment	Levinson and Gallagher (2007)
Professionals learn from errors	Fallowfield and Jenkins (2004) Field and Copp (1999)
Professionals can be given support	Fallowfield and Jenkins (2004)

Functions	Reference
Creating an environment where patients, their support persons, health care professionals and managers all feel supported when things go wrong	Australian Council for Safety and Quality in Health Care (2003a) Field and Copp (1999) Iedema et al. (2008)
Building investigative processes to identify why adverse events occur	Australian Council for Safety and Quality in Health Care (2003a) Iedema et al. (2008)
Bringing about any necessary changes in systems of clinical care, based on the lessons learned	Australian Council for Safety and Quality in Health Care (2003a) Iedema et al. (2008)

The other goal of implementing open disclosure that authors frequently mentioned is to bring about systems improvements that may help reduce errors (Reason, 2000). It is generally acknowledged that blaming individuals is unhelpful in reducing the incidence of medical errors. The official position is, instead, that the focus should be on establishing systems of organisational responsibility while at the same time maintaining professional accountability (Australian Council for Safety and Quality in Health Care, 2003a; Iedema, et al., 2008). The Australian Standard sees open disclosure as a method of encouraging the reporting of adverse events that will lead to opportunities for systems improvement (Australian Council for Safety and Quality in Health Care, 2003a). (See Appendix B for an example of where patient advocacy brought about systems change, albeit not under open disclosure.)

A goal of implementing open disclosure that is mentioned surprisingly seldom, is that it is a manifestation of patient autonomy. Patient autonomy is not only a fundamental ethical principle (Allan, in press ; Beauchamp & Childress, 1994) but is what patients want. Hobgood, Peck,

Gilbert, Chappell, and Zou (2002) who surveyed the opinions of 258 emergency department patients found that 78% of patients wished to be informed of adverse events immediately. Other researchers similarly found that patients expect timely discussions, and collaborative problem-solving and planning (see, e.g., Duclos, et al., 2005).

2 The key success factors for open disclosure

2.1 For professionals

Various authors address the ways in which open disclosure may occur successfully in an effective way. These processes are often articulated in handbooks (Australian Council for Safety and Quality in Health Care, 2003b), policy templates (e.g., Disclosure Working Group, 2008), or best practice guidelines (e.g., Fallowfield & Jenkins, 2004; Kraman & Hamm, 1999). The procedures usually include aspects of communication between professionals; professionals and patients and patients' families; and professionals and their managers (e.g., Australian Council for Safety and Quality in Health Care, 2003a; Disclosure Working Group, 2008). An overarching guideline is that effective communication should start at the beginning of an episode of health care and continues throughout the entire episode. In other words, professionals should always communicate in an open and ethical manner.

Kraman and Hamm (1999) suggest that after the occurrence of the adverse event the potential negligence, or malpractice should be identified by a risk management committee. This committee would scrutinise the facts by interviewing the involved professionals, the chief of the relevant clinical service, and other personnel as needed. If found that malpractice or error led to the loss of a patient's functioning, earning capacity, or life, notification of the patient or next of kin is then planned. Initial contact is made via telephone usually by the chief of staff, conveying the seriousness of the matter and requesting that the patient or next of kin returns to the medical centre as soon as possible. In conveying the seriousness, one may mention that a mistake occurred and that an attorney may accompany the person. Kraman and Hamm continues to explain that:

The subsequent meeting is with the chief of staff, the facility attorney, the quality manager, the quality management nurse, and sometimes the facility director. At the meeting, all of the details are provided as sensitively as possible, including the identities of persons involved in the incident (who are notified before the meeting). Emphasis is placed on the regret of the institution and the personnel involved and on any corrective action that was taken to prevent similar events. The committee offers to answer questions and may make an offer of restitution, which can involve subsequent corrective medical or surgical treatment, assistance with filing for service connection under 38 United States Code, section 1151 (a law that confers service connection on the basis of disability resulting from medical care), or monetary compensation.

After the meeting, the patient, surrogate, or next of kin is assisted in filing any necessary forms and is given the names and numbers of contact persons who can answer any additional questions. If the patient or next of kin has not already retained counsel, they are advised to do so. The committee is then equally forthcoming with the plaintiff's attorney so that the attorney's review of the medical record will confirm the information that was volunteered. The facility's attorney and the patient's attorney work to reach an equitable settlement on the basis of reasonable calculation of loss (Kraman & Hamm, 1999, p. 967).

Fallowfield and Jenkins (2004) argue that it is important that the process should be guided by guidelines that are ethical, practical, and address patients' needs. They believe that the guidelines should have an empirical basis that should include an analysis of their face validity.

An Australian study by Iedema et al. (2008, p. 398) provides information regarding professional's perception of what leads to a good open disclosure process. Some of the factors identified by professionals are set out in Table 7.

Table 7: Characteristics of a good open disclosure process as identified by professionals

The process must:

- Be planned and/or closely supported by staff who have received open disclosure training or have experience in carrying out open disclosure
- Be managed and supported by staff with specialised administrative appointments (e.g. Patient Safety Officer)
- Involve senior clinical staff
- Be conducted by staff who have excellent communication and listening skills
- Be conducted in circumstances where clinicians involved in the adverse event have already established a good relationship and understanding with the patient and the patient's family

The process must:

- Be a sub-component of an established clinical governance system
 - Encompasses careful pre-planning, responding to patient needs, adequate follow-up, and internal as well as independent counseling support
 - Include consideration of paying for patients' and/or family members' immediate expenses
-

Iedema et al. (2008, p. 398) found that:

[for] staff, open disclosure practice was seen to harbour uncertainties, including what should trigger a formal response, the unknown impact on individuals' and the organisation's reputation, unclear legal and insurance implications, and unreliable support by colleagues for those carrying out open disclosure.

In summary it appears that professionals believe that open disclosure must be planned, managed and implemented by competent staff who must be well trained. The process must involve senior clinical staff and patients must be well prepared and supported, both emotionally and financially.

2.2 For patients and their families

At the moment there is a lack of empirical data to base guidelines on, and authors therefore rely on research about professional communication in other areas. Fallowfield and Jenkins (2004) for instance reviewed the published research on communicating sad, bad, and difficult news to patients. They found that patients found it helpful if professionals were confident; showed concern; were caring; and allowed them time to talk and ask questions. Families focused on the availability of adequate privacy when receiving news; the attitude and knowledge of the news bearer; and the clarity of the message being provided.

Iedema et al. (2008, p. 399) interviewed patients and their families to determine what they believed the requirements for effective open disclosure are (see Table 8).

Table 8: Characteristics of a good open disclosure process as identified by patients and their families

The process must:

- Allow staff to show respect to the patient (and/or family members) by offering an immediate and sincere apology
- Be conducted as much as possible by those originally involved in the patient's care
- Allow patients to appoint a support person
- Allow patients to indicate the matters they want to see clarified and action taken on
- Allow staff to give carefully structured feedback as matters come to light rather than delaying feedback until the end of a closed-door investigation
- Prevent the fragmentation of health care by
 - a) accounting for staff who move to other institutions
 - b) preventing different staff expressing conflicting perspectives on the causes of the unexpected outcome
 - c) preventing revelations of adverse events being made by staff at alternative institutions without pre-emptive communication with the facility where the original care was provided
 - d) minimising different staff engaging consumers in repeated questioning about the case
- Be deployed as a formal process for all high-severity adverse events

- Involve staff who are good listeners and ensure patients and family members have the opportunity to express their grief, guilt, and/or anger
 - Be carried out in a way that is sensitive to consumers' culturally and linguistically diverse backgrounds
-

Patients and their families wanted open disclosure to be used for all high-severity adverse events and wanted staff to show respect to patients by apologising; accommodating the cultural and linguistic needs; provide them with support people; and giving them a voice about what issues they want action to be taken about. The open disclosure process must be conducted by those originally involved in the patient's care who are well informed and can therefore give comprehensive and accurate information and who have good communication and consultation skills.

Iedema et al. (2008) found broad support for open disclosure among professionals, patients and their families.

3 Barriers to open disclosure

There is a dearth of empirical information regarding the barriers to open disclosure and what authors present is therefore generally based on anecdotal evidence or their own speculation. Table 9 presents some of the barriers identified throughout the literature. By far the most compelling description of the barriers to open disclosure is provided by Wei (2007).

Table 9: Barriers to Open Disclosure Occurring

Barriers	Reference
Litigation fears – malpractice liability	Fallowfield & Jenkins (2004) Hoy (2006) Lamb (2004) Wei (2007)
Disciplinary criticism and/or action as a result of disclosure	Fallowfield and Jenkins (2004) Wei (2007)
Lack of commitment by top management	Fallowfield and Jenkins (2004)
Lack of explicit staff and manager support	Fallowfield and Jenkins (2004)
Being reported to external organisation or public registry	Hoy (2006)
Not knowing how to talk to patients regarding error	Corrs Chambers Westgarth (2002); Hoy (2006)

Barriers	Reference
Non-government hospital and health care providers malpractice insurers wishing to reduce settlement costs	Kraman and Hamm (1999)
Lack of institutional support	Lamb (2004)
Fear of risk to reputation	Lamb (2004; 2007) Wei (2007)
Loss of respect from peers/colleagues	Wei (2007)
Disclosure “gap” between information patients desire and what professionals provide	Levinson and Gallagher (2007)
Morbidity and mortality conferences being a chance to present interesting cases rather than reporting errors	Wei (2007)
Anxiety of exposing individual fault	Wei (2007)
Fear of loss of referrals	Wei (2007)
Social norms - such as the prohibition of criticism amongst professionals. That is, the patient is the responsibility of the supervising/consultant physician, thus other physicians privy to information feel they are not in a position to comment	Wei (2007)
“...so called whistle blowing can leave the individual exposed to victimisation, disciplinary action, or even dismissal...”	Walshe and Shortell (2004, pp. 106-107)

Barriers	Reference
“Club Culture” where physicians may encompass a culture of secrecy and protectionism	Walshe and Shortell (2004)
Variations in legislative protection between jurisdictions may lead to uncertainty in relation to admission of liability, particularly for those moving within states in Australia	Iedema et al.(2008)
Lack of training of medical students and staff	White et al.(2008)

It appears as if the barriers mentioned in the literature can be grouped together in five clusters.

3.1 Individual level

At the *individual level* there is the fear by professionals that by being honest they will expose themselves to litigation and disciplinary action; their reputation will suffer; and that they may suffer financial hardship due to a loss of referrals.

3.2 Intrapersonal level

At an *intrapersonal level* some professionals may feel anxious about admitting mistakes or feel incompetent to undertake an open disclosure process.

3.3 Organisational cultural level

Various factors have been identified at an *organisational cultural level*. There are suggestions that professionals appear to feel that there is a lack of managerial and institutional support for professionals involved in open disclosure procedures.

More controversial is the opinion of two professors of health policy and management, Walshe and Shortell, (2004, p. 107) who believe that the most important barrier to disclosure is "...the endemic culture of secrecy and protectionism in health care facilities in every country. There is a pervasive 'club culture' in which at least some doctors...prioritize their own self-interests above the interests of patients."

3.4 Meta level

At a *meta level* Walshe and Shortell, (2004) allege that many institutional administrators operate in a defensive manner in order to protect the institution rather than its patients, which is a message portrayed in several other articles (Levinson & Gallagher, 2007; Pierce, 2006).

3.5 Professional level

At a *professional level* there may be a lack of understanding of what the real purpose of open disclosure is (viewing it as an opportunity to discuss interesting cases for example) and what the real needs of clients are. Coupled with this is professionals' concern about communicating with patients and the families: "there is a great deal of uncertainty and confusion among health care providers about the do's and don'ts of open disclosure following and adverse event. Health care professionals may be unclear about what they can and cannot say to patients and their cares when something has gone wrong" (Corrs Chambers Westgarth, 2002, p. 2).

4 Findings

The definition of open disclosure in the different countries is not exactly the same, but most emphasise open and honest communication with patients and their families after an adverse incident. Studies conclude that open disclosure has economic advantages and that professionals, patients and families support it. Researchers argue that for open disclosure to be effective, open communication should start at the beginning of a health care episode and continue throughout. In other words, professionals should always communicate in an open and ethical manner.

Outcome studies evaluating the effectiveness of open disclosure in achieving its goals are quite scarce. The outcomes that have been investigated to date seem to relate mainly to the economic advantages. The seminal example of open disclosure's success comes from the Department of Veterans Affairs, Lexington, Kentucky, USA. Research emanating from the relevant facility shows that in one year prior to the introduction of open disclosure; two claims cost the centre US \$1.5 million. In the 7-year period of analysis after implementation of open disclosure policy, the facility had 88 malpractice claims. The cost of these claims to the centre averaged US \$190 000 per year – a total of US \$1 330 790 for 7 years (Kraman & Hamm, 1999).

4.1 Need for empirical evidence

This literature review reveals that there is a lack of empirical evidence, especially quantitative evidence, regarding:

- the factors required for successful open disclosure;
- whether using open disclosure brings about any measurable advantages for those who its supporters say it will bring benefits;
- the barriers to the use of open disclosure; and
- the needs of patients, families, professionals and institutions when involved in open disclosure.

5 Recommendations for further research

The following research questions requiring further investigation have been identified:

1. Is organisational culture a barrier to the implementation of open disclosure?
2. How does an organisational culture have to change in order to adopt open disclosure?
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7. Does open disclosure bring about actual financial savings?
8. What is the impact on professionals who engage in open disclosure proceedings?
9. What support do professionals require in order to facilitate the open disclosure process?

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Appendix A

Industry partners

The following industry partners have either been involved in the Western Australian open disclosure collaboration or have contributed to the funding:

- Australian Commission on Safety and Quality in Health Care;
- Australian Medical Association (WA);
- Avant Mutual;
- Edith Cowan University;
- Health Consumers' Council;
- MDA National;
- Office of Health Review;
- Ramsay Health Care;
- RiskCover;
- St John of God Health Care;
- Val Lishman Foundation for Health Research, and
- WA Department of Health.

Appendix B

Patient advocacy and systemic change

One of the most striking examples of patient advocacy leading to systemic change is the case of “Patient A” in Lamb (2004). Patient A was diagnosed and treated for cervical cancer, however, she discovered that 4 previous cervical smears that had been reported as normal or inconclusive showed evidence of cancer. Earlier detection of Patient A’s cancers may have led to her treatment being significantly less invasive and consequent health difficulties reduced or completely avoided. Patient A tried going through the appropriate channels to complain as a result of her fear for other women who may have been misdiagnosed as well. When Patient A found that she was getting nowhere she decided to take the matter to the courts. Eventually the matter became public, resulting in the 2001 Gisborne Cervical Screening Inquiry which led to many improvements in the national cervical screening programme in New Zealand. This systemic change was not the result of open communications following open disclosure principles. Patient A mentioned to the author that if the matter had been dealt with in an open, honest manner that she would not have pursued the matter for so long and her actions would have been different – particularly if she received an apology and her concerns regarding other women were addressed more rapidly and comprehensively (Lamb, 2004). It was systemic change that seems to have been the main goal for Patient A – not personal issues.