



Independent Living Resource Centre

ADVERSE HEALTH EVENTS

Submitted to: *The Task Force on Adverse Health Events*
Suite 1100
West Block, Confederation Building
P.O. Box 8700
St. John's, NL
A1B 4J6



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Submitted by: Independent Living Resource Centre

Date: June 13, 2008

Independent Living Resource Centre (ILRC)

The Independent Living Resource Centre (ILRC) is a resource centre designed by and for people with disabilities. The centre is open to anyone with any type of disability and of any ages. We offer a wide range of disability related information, services and resources. Our goal is to support people living with disabilities in making informed decisions about their lives.

Independent Living (IL) History

The Independent Living movement arose from the opposition to the institutionalisation that many people with disabilities once faced. The institution, born from a paternalistic impulse and an over-reaching medical view in which a person is transformed into a patient, provided a rigidly controlled life that was separate from the community. Simply stated, Independent Living can be understood to be the institution's exact opposite.

The Independent Living (IL) philosophy is based on the premise that all people with disabilities have skills, determination, creativity and a passion for life. The IL philosophy also acknowledges that many people with disabilities are still today unable to fully participate in the economic, political and cultural life of community because barriers to full citizenship persist in Canadian society – outdated attitudes, inflexible laws and regulations, and fragmented and uncoordinated approaches to everything from disability related supports, to housing, to public transportation, to access to health care services. The IL philosophy is not an abstract concept. Instead, it is about a “way of living” as a person with a disability in a society full of barriers, an ongoing dynamic process that addresses the intersection between barriers, gaps, skills and supports at both an individual and systemic level.

Pre-amble

One of the words that call us back to our existence within the institution is the word patient. We prefer to call ourselves consumers. The word consumer is, first of all, a word we have chosen. In opposition to the

word patient, a word with overtones of dependence and passivity, the word consumer emphasizes our role as *active* and *informed* consumers of products, programs and services. We are consumers of disability related supports, and we are consumers of health care services.

Words are important. We are not only replacing one term with another, we are changing our role and our expected contribution. The first reality we are facing in the current health care system is simultaneously it's most challenging and promising reality – the changing role of the 'patient.'

There is a lesson to be learned from the story told by people living with disabilities (hereafter *consumers*). Its theme you will see in each of the areas of this report. As we have moved beyond definitions that confine us within our disability, so the 'patient' is moving beyond their limited role as receiver of care. In the eyes of a government that promotes an open and participatory citizenship, we need a cooperative approach that values everyone's place within the system. For alone, no one person can hope to make perfect decisions, but together, we can hope to make good decisions arrived at with transparency and respect.

Introduction

In preparation of this submission to the Task Force on Adverse Health Events the ILRC ensured that consumers had an opportunity for their voice to be heard. The ILRC facilitated a focus group of 27 consumers, to discuss how the health care system identifies, assesses, discloses and takes action on adverse events, as well as their experiences and recommendations of how effective communication can facilitate this process. The attached list of questions was used as a template to lead the discussions. Please see Appendix "A."

Identification of Adverse Health Events

1. a) "I can usually identify a problem."

- Consumers want to have the opportunity to identify adverse health events.

b) "I want any problems dealt with by the person in my health care directive. After all, I've chosen that person because they are knowledgeable and I trust them."

- Consumers with advance health care directives have planned for the possibility that they will be unable to control the course of their treatment. Under these circumstances, they have selected a substitute decision maker that will identify adverse health events on their behalf.

c) Many consumers noted that they had identified an adverse health event – such as inappropriate treatment in the emergency room – but there was no record of it in their chart.

- Consumers often identify adverse health events to their health care providers. In this case, consumers want the identified adverse health event to be marked and noted in their charts. There needs to be a record or paper trail that draws attention to the adverse health event.

d) “My rehabilitation specialist is the ‘only game in town.’ I don’t feel comfortable challenging him again and again. I need these services for life.”

- Some consumers do not feel comfortable identifying adverse health events to their health care provider. Often in these cases the consumer is dependent on the service provided by that particular health care provider. It may be that the health care provider is the only specialist that provides that particular service to the consumer, the consumer lives in a rural area served by one main health care provider, or the consumer relies on treatment from that health care provider for the rest of their life.

e) Consumers need an alternate *safe* way of reporting adverse health events, especially when there is a dependence on the one health care provider.

- In these cases, it is still essential to give the consumer the opportunity to identify possible adverse health events, while allowing the consumer to maintain anonymity, at least in the eyes of the health care provider in question. Again, there should be a record and paper trail of the identified adverse health event as said trail helps coordinate a response, and ensures that the consumer’s identification of the adverse health event is acknowledged.

2. a) Consumers have indicated instances where secretaries for doctors have prevented a potential adverse health event.

- Adverse health events should be identified by whichever health care provider discovers it. If any health care provider identifies an adverse health event, they should notify the main health care provider immediately. Again, the identified adverse health event needs to be recorded and documented. The goal is to minimize harm to the consumer.

b) "...Nurses may be the ones to identify the problems but they have no say... doctors find it offensive that...nurses could even question their judgement."

- Some health care providers may not feel comfortable identifying adverse health events, especially if they work under the supervision of the main health care provider. A system that promotes identification of adverse health events by *any* health care provider, regardless of rank, is essential. Anonymity would ensure that the subordinate health care provider is protected and feels safe enough to identify adverse health events.

3. "I was perched high up, when they gave me a needle. They didn't make sure I was safe and I nearly fell."

- Consumers have identified that lack of accessibility has led to adverse health events or potential adverse health events. Exam tables are notoriously inaccessible. In particular, it can be difficult for wheelchair users to get on or off the tables. Add to that the increased difficulty consumers face when they have broken limbs or are experiencing dizziness. Consumers have indicated that it makes them feel unsafe.

4. "You have to be persistent."

"Yes, you have to be persistent in advocating for everything. Sometimes...I feel so tired."

- Consumers have had to repeatedly identify what they need if they are to avoid an adverse health event. Their required persistence implies that they are working against attitudes that are pervasive in the system. These systemic attitudes endorse the belief that the health care provider always knows what is best for the consumer. The experience that the consumer has gained through living with their disability, and how that experience informs their knowledge of their required health care is not sufficiently valued.

Assessment & Adverse Health Events

1. a) "There is pressure placed on me to just get in a chair and give up

trying to walk.

- Consumers' assessments of their health care delivery and the health care providers' assessments of the same often vary greatly. The gap between the two may lead to the suppression of an adverse health event as identified by the consumer. Health care providers should try to see the consumer's point of view.

b) "I think the provincial government should hire two or three 'patient' advocates, with the autonomy to report problems."

- Consumers who face this gap often feel frustrated, invisible and powerless. To overcome this obstacle and to help with the unpleasant feelings evoked by this dissonance, consumers indicate that they would like to have access to a 'patient' advocate. This advocate would represent the interests of the consumer and furthermore, should have knowledge of the independent living model and the disability rights movement. Supplying this advocate for the consumer is essential as it provides them with the support necessary to share what is often a difficult story.

c) When consumers have a contribution to make, and when that contribution is nurtured and valued, the system is improved.

- Involving consumers in the assessment of their health care delivery will not only increase the responsiveness of the health care system, but it will also increase the public sense of confidence in that same system. Ultimately, by providing support to consumers, they can share the wealth of knowledge they have with their health care providers. Consumers move beyond the role of patient and into the role of a contributing peer.

2. "I told my doctor the equipment was inappropriate, but my opinion was not valued. I only received new equipment after showing him the sores."

- Often, a consumer's assessment of their treatment is only taken seriously when they have proof in the form of an adverse health event. In this case, the adverse health event is usually physically observable; if it were not so, the consumer would probably

continue to endure the underlying cause of the adverse health event – the health care provider’s reluctance to acknowledge the consumer’s insight into what constitutes appropriate treatment.

3. a) “The doctor took one look at me and said my headache was because of my shunt, when I didn’t even have one.”

- A consumer’s disability often skews the assessment of the health care provider. Often the assumptions of the health care provider put the consumer at risk for an adverse health event.

b) “Upon reporting to the ER with chest pains, I had to insist that they remove the mental health label from my chart, and then I had to insist they classify my insistence as something other than agitation brought on by my mental health concerns.”

- Consumers of mental health services experience this time and again. They may present themselves to an emergency room with a concern unrelated to their mental health, but upon disclosure of the medications they are taking, “mental health” is written across their file as their reason for visiting the ER. The effect of this assessment is two-fold. First, the wrong focus may lead to inappropriate or delayed treatment that causes an adverse health event. Second, the consumers increased stress while confronting these assumptions is in itself an adverse health event.

c) “Because of my disability, my specialist may say that there is no treatment as the symptom is related to my disability. I discover later that there is a treatment and that more investigation could have shown it. ”

- A consumer’s disability can cause tunnel vision in the health care provider. Their assessment may relate many or any symptoms to the consumer’s disability when another underlying cause may be responsible. Sometimes the health care provider may not treat the symptoms, as they believe the symptoms are caused by the disability, which may have limited treatment options. Again the consumer experiences an adverse health event, one filled with discomfort and pain.

Disclosure of Adverse Health Events

1. Most consumers have never had their health care provider disclose an adverse health event; however, most consumers have identified that they have experienced an adverse health event. This gap needs to be addressed if consumers are to regain their faith in the current health care system.
2. Consumers recognize that disclosure should occur as soon as possible, that it should be delivered by the most appropriate – often main – health care provider, and that it should be done face to face.
3. Consumers also acknowledge that an apology goes a long way. It lets the consumer feel human again.
4. Consumers realize that health care providers make mistakes and that the health care system may occasionally produce an adverse health event. It does not serve the health care provider or the health care system to deny this fact. Consumers would be more sympathetic towards their health care providers if they acknowledged their failures.

Evaluation & Response to Adverse Health Events

1. a) One consumer who had lost his leg because he received the wrong medication says he still does not know if he had to lose it. There was no evaluation after the fact.
 - Consumers have noted that they often fail to see a response to their adverse health event. It may be that the current reporting system prevents the identification of the adverse health event in the first place. It is also possible that the response to the adverse health event and the system that evaluates what an appropriate response should be does not include the consumer as an active and important decision maker.
- b) “I have had to walk in on consultations about me that were never meant to include me.”
 - At a more fundamental level, evaluations and multi-party

consultations between health care providers about consumers have been carried out without the attendance of the consumer. If consumers are not included in their own evaluations, what chance is there that they will be involved in a more general and systematic review?

2. Transparency of the entire process is essential.

- The response should be observable and its rationale explained to the consumer it concerns. If the response has occurred 'behind the scenes,' then an explanation of how the response will help prevent similar adverse health events in the future is needed. In short, if you involve the consumer and respond to them, you create a health care system that is respectful and responsive.

3. "I had to bring a TV crew to my appointment to document the inaccessibility of the facility and the procedure. I received an apology, but nothing has changed."

- Some consumers have received written apologies for inaccessibility, only to discover that the facility they attended and the treatment they received are still inaccessible. Similarly, consumers have indicated that they have encountered the same adverse health event again and again (ex. continually being turned away from the ER when reporting as a consumer of mental health services). Consumers need to know that neither they nor their peers have to continually face the same obstacles over and over.

4. "Do you know what it is like to walk in my shoes?"

- The health care provider should have training that allows them to see the situation from the consumer's perspective. As well, the process for evaluating health care professionals should try to ascertain what role they believe the consumer should play. This evaluation itself needs to respect the consumer and allow them to play a role. Involving the consumer as an active and important member of a transparent evaluation process will lead to a more appropriate response to adverse health events.

Communication and Adverse Health Events

1. Communication plays a very important role. Effective channels of communication can;
 - prevent an adverse health event
 - ensure fewer adverse health events go unreported
 - decrease the impact of an adverse health event by increasing the support provided to the consumer during the process
2. To ensure effective communication with consumers, health care providers should speak in plain language whenever possible, provide information in whatever format the consumer identifies and remember to speak to the consumer and not their attendant.
3. “They tried a brace and that didn’t work, they tried popping it back in and that didn’t work, they talked about surgery but nothing has happened. Now they don’t say anything.”
 - Health care providers do not handle failure well, and it is disappointing that communication often breaks down after an adverse health event occurs. Consumers want to feel that they matter and that they are important. Often all it takes to help the consumer feel respected is for the consumer and their situation to be acknowledged.
4. Sometimes adverse health events have happened due to language barriers. Readily available sign language interpreters are essential for persons who are deaf to ensure that what they are communicating is understood and the information they are receiving is accessible.

Appendix "A"

Adverse Health Events Questions to lead discussion

1. Who *identifies* problems that occur during Health Care Delivery?
You? Your family? Government? The media?
 1. Do you feel comfortable *identifying* a problem you have encountered during Health Care Delivery? Would you feel more comfortable identifying the problem after the fact?
 2. Do you feel comfortable with your family *identifying* a problem with your Health Care Delivery?
 3. Do you feel comfortable with the Provincial Government *identifying* problems during Health Care Delivery? Should they have a greater or lesser presence in the identification process?
 4. Do you feel comfortable with the role of the media in *identifying* problems that occur during Health Care Delivery?
 5. Are there appropriate channels through which one can *identify* problems occurring during Health Care Delivery?
 6. What would make *identification* of Health Care Delivery problems easier?

2. Does your *assessment* of your treatment match your health care provider's *assessment*?
 1. If there were discrepancies between the two *assessments*, were you taken seriously? Were there other channels to turn to?
 2. How could the *assessment* of problems that occur during

Health Care Delivery be improved?

3. Has your health care provider ever ***disclosed*** a mistake or omission in treatment?
 1. Was this ***disclosure*** handled properly? Respectfully? Promptly?
 2. After this ***disclosure***, were you informed of your options? Did you feel that you had any options?
 3. How would you feel if this ***disclosure*** was not provided to you first?
 4. Whose responsibility is it to see that ***disclosure*** occurs?

4. Was there a ***response*** to the problem that occurred during your treatment?
 1. What was the ***response***?
 2. Was the ***response*** appropriate?
 3. Did the ***response*** come quickly?
 4. Was the ***response*** observable? If not, were the “behind the scene” ***responses*** explained? Was the process transparent?
 5. Do you think the ***response*** was effective? Do you think that someone else would still encounter the same problem? Have you ever faced the same problem again and again?

5. Do you think the lines of ***communication*** were open during your experience?
 1. Was information ***communicated*** to you effectively? Quickly? Completely?
 2. Did you notice failures of ***communication*** between health care providers? From nurse to nurse? From nurse to doctor? From doctor to nurse? From doctor to doctor? From doctor to lab? From lab to doctor? From doctor to rehabilitation specialist? Between specialists?
 3. What should be done when lines of ***communication*** fail?
 4. Whose job is it to ensure effective ***communication*** occurs?

6. Was there an ***evaluation*** of the entire process?
 1. Was it respectful? Effective? Transparent?
 2. Were your rights the central concern of the ***evaluation***, or did you feel left out of the process? Was it responsive to your input?
 3. Was there an opportunity to review the ***evaluation*** process? Was it unbiased? Was it done by a third party?

7. Why do you think these problems arise during Health Care Delivery?
 1. Was your input actively sought at each stage of the process?
 2. What questions/concerns would you address to the Premier? Minister Ross Wiseman (responsible for The Department of Health & Community Services)? The Task Force on “Adverse Health Events” (i.e. Problems that occur during Health Care Delivery)? Eastern Health and other Regional Health Authorities? Doctors, Specialists, Nurses?
 3. What needs to happen to ensure we have the best possible Health Care system?
 4. Should there be a well defined “Quality Control System”?