Feedback from Associate Professor Bronwyn Hemsley
The University of Newcastle, NSW Australia
Chief Investigator: “Keeping People with Communication Disability Safe in Hospital” NHMRC Project Grant 2013-2016.

On the document:
Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework

I also attended a public meeting in Newcastle NSW 14th April 2015 to provide feedback.

Low quality services can still be safe, and safety incidents occur in high quality services. Care quality does not guarantee care safety. Therefore, low medium and high quality services all need to adopt some form of ‘safety framework’ that works to predict and prevent ‘safety incidents’ that are possible in that service, and for reporting of harmful and non-harmful incidents including near miss incidents, and follow-up of safety incidents to (a) investigate why an incident occurred, what led up to the incident, (b) put into place any procedures to prevent such incidents occurring in the future (follow-up), and (c) monitor the person or people involved as part of the follow up, to provide ongoing support, guidance, or compensation in regards to the incident. Follow up should include the usual legal channels available wherever appropriate, in relation to safety incidents where the police or other relevant authorities in the matter should be notified.

Systems for complaints are not an efficient way to investigate safety, as it is likely the complaints will not reflect the full range of incidents occurring, and may not even reflect the most serious incidents. Complaints will also not reflect what is happening for people who have communication impairments, who have difficulty expressing a complaint or communicating with non-familiar listeners who take complaints. Complaints systems are useful and important, but are not sufficient as ways to understand what is happening in a system/service in regards to its safety for service users and staff.

Complaints are only one way of detecting when a system is ‘potentially failing’ or ‘failing’ the system users. Most people will not complain, for fear of receiving a worse service, or having services reduced. Complaints are usually seen as a ‘last resort’ by desperate people who are at a stage where they are willing to risk a worse service or loss of service for the sake of being heard. People who are willing to take the risk are also willing to ‘suffer the consequences’ but should not be made to feel that they are in the wrong by highlighting an error. Rather, people who complain need to feel that their information is highly valued and protected from any negative consequences of them having raised the alarm. A culture of safety can be fostered through people being invited to submit any problems or complaints no matter how small, if they relate to safety this information can promote awareness of incidents, and of the factors contributing to ‘near miss’ events. In a culture that supports safety, reporting of near miss or potentially harmful incidents is seen as a way to ‘keep the environment safe’ and prevent future serious incidents. To focus only on reporting of serious incidents is to neglect the value of reporting and examining other ‘red flag’ incidents that herald future problems - and which if ignored are seen in retrospect as missed opportunities for improving safety in the system. In any newly implemented system, it is a good idea

to seek *feedback* and not only reporting of incidents, including witness reports or first hand accounts of *anything that has gone wrong* so as to develop a category or catalogue of the types of things that can go wrong, and what might predict or prevent these from occurring in the future. For this reason it is very important to develop a way of capturing information in the early stages of the new system, so that a greater amount of data can be used in forming the categories. Some safety incidents will be uncommon and more harmful or involving permanent harm, some will be common and harmful or non-harmful, and some will be frequent but not harmful - or at least with temporary and not permanent harm. The vast majority of safety incidents reported might be the common non-harmful type, but these being known can help to understand what leads up to the less common or more harmful incidents, through understanding factors within environments and individuals - in various combinations - that lead to something 'going wrong'. In healthcare systems, a database of incidents for reporting is an important way of gathering data on safety. Have a look at the Incident Management Systems (IIMS in NSW) for an example of a voluntary reporting database. Information and reports on IIMS are available here:
http://www0.health.nsw.gov.au/policies/pd/2014/pdf/PD2014_004.pdf

The question then would be, what would be the categories for a *disability service* as opposed to or aligned with a *health* service - particularly when disability services provide *care* and in some cases quite a high level of *nursing* type care to individuals with chronic health conditions in residential care services.

Other comments:

1. Access to information - need Internet online but also hard copy resources (books).
2. How long has the service existed, are they local?
3. Checklists or suggested interview guides for people to determine information directly with the provider (regarding safety/protections/safeguards/risks etc).
4. Trip advisor concept: no controls over who reports; testimonials and anecdotes must be taken in context of not being verifiable.
5. Agency - how responsive is the agency to providing the staff that have been requested?
6. What public reports are available on the service's safety?
7. Information in accessible formats and access to communication supports
8. Information on how to judge the quality of information provided by service providers - that is, how to screen out 'testimonials' and seek factual data that can be verified or checked up by other sources.
9. Accessible to all information - but what kind of information will there be about safeguards/safety/warnings of possible dangers?
10. Building capacity of individuals, families, siblings - in regards to 'safety knowledge' - being safe and avoiding risks of harm.
11. Weighing up risks and harms; relative risks and relative harms; and means to protect or reduce potential risks and harms.

Specific Feedback
p. 10. Paragraph 1
"... achieve their goals" and be safe.

Page 10 paragraph 3

“There is also a risk that people with disability could” experience preventable adverse circumstances with or without harm (i.e., both non harmful and harmful adverse events are to be avoided).

The structure of a national quality and safeguarding framework.

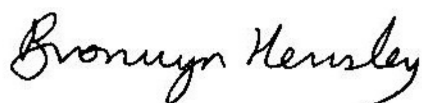
Developmental domain - seems to focus on the individual with a disability, but needs also to focus on the services and developing a culture of safety incident management (including incident reporting and follow up). Currently, the domain is saying ‘if you make yourself safe, then this is your best chance’. As such, it misses an opportunity for saying ‘if services make themselves more safe, then you have a better chance’. It is only with both elements of development occurring, that the system might be ‘made safe’ in the developmental period, so avoiding many of the preventable adverse events/incidents that could arise without such preparation.

The preventative domain needs to include an incident reporting system, for the analysis of incidents to determine what needs to happen to prevent future incidents. That is, learning from mistakes as a means to *prevent* further incidents; not only to see it as fully preventing incidents, but that examining incidents that have occurred is an important learning exercise to identify ways to prevent future incidents (circular).

Corrective domain: covers the ‘follow up actions’ that are taken *after* incidents. Complaints are actually *not* the primary thing that happens after incidents. Complaints are only one element and might not even arise. Therefore, the follow-up needs to be ‘feeding back’ strategies and actions to prevent future incidents for that person or other persons going through the same situations. Follow up might mean reviewing policies impacted by the incident, training, direction, and providing open disclosure and apology/compensation and so on, to victims or people negatively impacted by the safety incident. Follow-up or corrective action can also involve disciplinary action, or any other training that could help to prevent further occurrences (as in the preventative domain).

I am happy to provide further input as systems policies and procedures are developed, particularly in relation to the informing and involvement of persons with a communication impairment and their families.

Best regards,



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