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The Death Dilemma

A Submission to the Family and Community Development Committee

Abstract

A significant number of deaths are occurring annually in the disability accommodation sector. Although reporting deaths is mandatory, both in the context of incident reporting as well as to the Coroner, nonetheless, people with disabilities dying in residential settings has received little attention.

This submission draws the death dilemma to the attention of the Parliamentary Inquiry in the hope that at long last someone with power will ask – Why so many deaths? Further, that the Inquiry will challenge the variable categorisation of deaths and the lack of transparency in public reporting.

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THE DEATH DILEMMA

Reporting Deaths

1. Many deaths are occurring annually in the disability accommodation sector. Despite mandatory reporting of deaths, there has been almost total silence on people with disabilities dying in residential settings.

2. Why is that there is, on average, five plus deaths occurring every week? The Inquiry must bring this significant issue to the forefront. The Inquiry must challenge why there is a variable categorisation of the reporting of deaths and why there is a lack of transparency in public reporting.

3. The current reporting of deaths of people with disabilities while in the care of Department of Health and Human Services (the Department or DHHS) and funded community service organisations' residential facilities fails the transparency test. This failure raises serious question as to what may have occurred in relation to each such death.

4. The combined number of people with disabilities who are supported in DHHS and funded sector residential facilities is currently approximately 5,040. Although the Coroners Act requires deaths that occur in care to be reported to the Coroner, DHHS also requires deaths to be reported via its incident reporting system.

5. The DHHS website identifies the objective of incident reporting as enabling *'Service providers to take prompt corrective-action to protect the wellbeing and safety of clients where necessary and better understand the underlying causes of incidents to prevent their recurrence'.*

Incident Reporting

6. During the 1980s the Department introduced compulsory incident reporting. This system required incidents to be reported according to a particular category, as in Category 1, Category 2 or Category 3.

7. The Department now defines Category 1 incidents, which are the most serious, as *'the most serious incidents and include incidents such as death of clients; allegations of physical or sexual assault; and serious client behavioural issues that impact on client or staff safety'*.

8. Despite this descriptor, the requirement for reporting particular deaths was changed in December 2011. The writers understand it was the then Minister who issued the instruction for the change to occur.

9. The change meant that the original requirement for reporting all deaths as Category 1 incidents was changed to only reporting those deaths defined as *'unexpected or unexplained'.* All other deaths were, from that time, to be reported as Category 2 incidents.

10. Although this change went almost unnoticed, the change is significant. The significance, in part, is because those deaths that are not deemed to be '*unexpected or unexplained'* are not now reported as Category 1 incidents.

11. The writers can advise that when they sought advice from the Department as to the number of deaths that occurred for particular years but were not included in the Category 1 reporting, they were advised that such information was not readily available and would have to be compiled.

12. It must be assumed from this advice that if non-Category 1 deaths are reported as Category 2 'incidents', then the Department does not tabulate the figures. Further, it is unlikely therefore that any form of inquiry or investigation or

analysis is undertaken. If this assumption is accurate, then what it suggests is that the Department treats such deaths in care as incidental matters not worthy of any form of follow-up.

The Significance of the Change in Reporting

13. The change in reporting deaths as noted in 9 above has created two dilemmas. The first is that only those recorded as Category 1 incidents are now publicly disclosed while all other deaths, as noted in 12 above, are hidden from public scrutiny.

14. The second relates to the fact that the true number of deaths occurring on an annual basis in disability accommodation is not now revealed. Table 1 below is reproduced from the *Equal Opportunity and Human Rights Commission – Beyond Doubt Report* released in July 2014 p.90. This table is significant in supporting this view.

Table 1:

Category one critical incidents by incident type group in Disability Services

Category one incidents	2009-10	2010-11	2011-12	2012-13
Client deaths	208	272	156	65
Assault	287	396	439	413
Behaviour	46	52	91	113
Other incident types	451	876	1,010	1,199

15. Given the reporting arrangements changed in December 2011, the writers submit that it is reasonable to assume that the 156 deaths publicly reported for 2011-2012 comprised those reported under the full disclosure rules for the period July to December 2011 plus only Category 1 reported deaths for the second half of that year, January to June 2012 inclusive. However, not included in the figures for the second half year were those deaths not identified as *'unexpected or unexplained'*.

16. The 65 deaths reported as Category 1 incidents for the full year 2012-2013, were recorded in accordance with making public only *'unexpected or unexplained'* deaths.

17. The significance of the dilemma is highlighted further by the fact that, as per the Department's website, only 84 deaths were publicly reported for the full year 2013–2014 as Category 1 incidents.

18. The figures 156 (2011-2012), 65 (2012-2013) and 84 (2013-2014) deaths as publicly reported annually from 2011-2012 are significantly less, on an annual basis, than the number of deaths as publicly reported for the previous two reporting years of 2010-2011 and 2009-2010. Again noting that it was midway through the 2011-2012 year the reporting requirements changed.

19. Thus, given the number of deaths that occurred in care and were publicly reported for the two years prior to 2011-12 as per Table 1 above, the reasonable assumption must be that the number of deaths has not dramatically reduced since 2010-2011. What must be reasonably assumed is that it is the change in reporting that has skewed the figures down from the 2011-2012 reporting year.

Causes of Client Death and Reporting

20. While it may well be the Department will argue that those deaths that are not reported as Category 1 incidents comprise what might be described as *'expected deaths'*, as in those people already had a condition which was likely to shorten

their life, nonetheless, it would be wrong to assume that all such deaths occurred in the context of nothing untoward having occurred.

21. Many deaths of people with disability who are clients of the Department or funded community service organisations may well be expected to die in care due to the age and medical history of the individuals.

22. The Department and funded community service organisations are required to report a client death as a Category 1 incident when the death occurs in an unusual or unexpected circumstance, for example, overdose, suicide or sudden fatal illness. For all deaths that occur in departmentally managed supported accommodation, the department notifies the Coroner and the Community Visitors Program managed by the Office of the Public Advocate.

The Size of the Dilemma

23. Given the failure of the Department to publicly release Category 2 Incident Report figures, where some of the death figures are located, it is not possible to be categorical in terms of how many people with disabilities are dying in supported accommodation facilities on an annual basis.

24. However, given that it is known not all deaths are reported as Category 1 incidents, it is possible to extrapolate from the last known full year figures when all deaths were reported as Category 1 incidents.

25. Therefore, by considering the two reporting years before the changed reporting arrangements in December 2011 and combining these totals and dividing by two, the writers submit that, on the balance of probabilities, the resultant figure is more likely than not to represent a fair and reasonable annual average that has credence for the current and recent years.

26. Thus, the combination of the 208 deaths that occurred in 2009-2010 and the 272 deaths that occurred in 2010-2011 represent a composite total of 480 deaths, **or on average 5+ deaths per week.**

27. The writers submit that by applying the above figures it is reasonable to conclude that 5+ deaths are still occurring every week.

28. Yet, despite this figure, the Secretary of DHHS, the Public Advocate, the Disability Services Commissioner, advocacy organisations and the Government appear to look on as disinterested spectators.

29. The writers ask – Why is it that deaths in custody and the abuse of children, neither denied as matters requiring investigation, nonetheless receive significant public and governmental attention while the deaths of people with disabilities in care goes unnoticed and unaddressed?

The Ultimate Dilemma

30. The death of a person while in the care of a government or funded service is clearly a significant incident. In part, this significance is emphasised by the fact that such deaths must be reported to the Coroner under the Coroners Act.

31. The ultimate dilemma however, is highlighted by the stringency of reporting requirement to the Coroner contrasted to the lessening of significance by the Department treating deaths in a variable manner, as though some deaths are of a greater or lesser significance to others.

32. Given the significance of death and its relationship to compulsory reporting to the Coroner as well as through the Department's incident reporting system, the writers submit that it stands to reason the deaths must be considered as a

separate category, which is stand-alone from the Department's Category 1, 2 and 3 incident reporting.

33. The writers further submit that all deaths must not only be reported under a single and separate category, but that the figures must be made public.

34. They further submit that the reporting must include the reasons for each death where the reason for each is established as the result of an independent investigation.

35. However, as a first order matter, the writers submit that the Inquiry must address the reporting of deaths and challenge why there is not total transparency.

36. The writers contend that the Inquiry's requirement to include '*but not be limited to: why abuse is not reported or acted upon; and how it can be prevented'*; should not preclude inquiring into the matter of the deaths of people with disabilities that are occurring in care.

37. The writers further contend that without knowing how many deaths are actually occurring, because not all deaths are being publicly reported, there is an absence of full transparency in terms of how each death occurs.

38. Given that it can reasonably be assumed that in excess of five people with disabilities are dying in care every week of every year, it must also be considered reasonable to assume that some deaths may have occurred as the result of abuse, neglect or violence.

39. Therefore, unless the Inquiry inquires into why over five people with disabilities are dying in care every week, then it will have failed the requirement of not limiting its brief.

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End of Submission

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