DEAD AND FORGOTTEN - DEATHS IN DISABILITY CARE

A Submission to the Parliamentary Inquiry into Abuse in Disability Services

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1. The deaths of people with disabilities living in residential care continue to be ignored.

2. In the context of Term of Reference A and the requirement of the Committee to consider the reporting of and action taken in relation to the abuse of people accessing services provided by disability services providers, including the Department of Health and Human Services, a shroud of secrecy exists in relation to the reporting of deaths.

3. "Reporting" is a requirement of service providers when the death occurs of a person with disabilities living in residential care. This is in terms of the DHHS incident reporting requirements. The reporting, however, lacks transparency, in that despite death being the most serious outcome that can occur for a person in care, the reporting of death has since 2012 been consigned to a two-tiered mode. Since then, only the numbers for the top tier, as in Category One deaths, which are defined as *"unusual or unexpected*" have been made public. Apart from the other deaths, which are required to be reported as Category Two, there is no way of knowing whether there is an investigative action in relation to any death.

4. It may well be that there is nothing untoward in many of the deaths occurring in disability care. However, it cannot and must not be assumed that abuse and neglect are not contributing factors in relation to the deaths of some people. Therefore, if the Committee is to truly address the issue of reporting and action taken in relation to reports of abuse and neglect, they must address the issue of the reporting and action taken in relation to deaths occurring in disability residential services, in order to be satisfied that abuse and neglect has not been a contributing factor in any of the deaths.

5. The issue of death must not therefore be simply considered as a statistic, or as a categorisation or merely a matter for reporting. It must be considered in the context of an action requirement. It is critical that the Committee addresses both aspects.

6. To do this, it is essential the Committee investigate the total number of deaths that have occurred in disability care since the change in reporting requirements in December 2011. It is essential the Committee appraise itself of how these deaths have been categorised, whether investigations have taken place in relation to each death, and what follow up actions, if indeed any, have been taken in the event of any of the deaths being associated with abuse and neglect.

7. It is critical that the Committee does not simply dismiss deaths in the way the Department has categorised them, by simply accepting that some are "unusual or unexpected". The writers contend in the strongest voice possible that deaths which occur as a result of, for example, mismanagement of medication, the failure to vitamise food and as a result choking occurs, or dehydration, are care matters that, if not addressed properly, constitute neglect and therefore abuse.

8. Apart from the above, which might be argued by some to be not worthy of investigation - although the writers challenge this as being naive and dismissive – it cannot be assumed that those deaths that are categorised as "*unusual or unexpected*", for example, death by suicide or overdose or a sudden fatal illness, as referenced by DHHS in its additional human services delivery data, will automatically lead to an investigation.

9. Based on the Category One figures of deaths occurring in disability residential services, Table 1 below shows that since the separation of deaths into two categories, 219 deaths have occurred in the past three years in the category of "unusual or unexpected".

10. What the table does not show however, and indeed cannot show, is - the total number of deaths? This is because figures are not made public for those deaths that since 2011-12 have been reported as Category Two.

Table 1: **Category One Incidents – Deaths**

2009-10	2010-11	2011-12	Total 2009-12	2012-13	2013-14	2014-15	Total 2012-15
208	272	156 (Note)	636	65	84	70	219

Note: In December 2011 the reporting requirements changed so rather than all deaths being reported as Category One, some were required to be reported as Category Two.

10. While of course the total number of deaths is significant, as is their reporting and investigation, the significance of deaths in the context of the Committee's brief is to:

- Inquire into how deaths are reported
- Ascertain why deaths are categorised, with some being Category One and some being Category Two
- Ascertain what constitutes "unusual or unexpected"
- Expose why the death figures in Category Two are not made publicly available
- Inquire into whether or not investigations are undertaken, either or both by the agency who provided services or the department
- Ascertain whether any, and if so how many, deaths may have been associated with abuse or neglect pushed aside.

11. Given this, the Committee is not only urged to address the above points listed above, but the Committee must also make recommendations in relation to the reporting, investigation and other follow up as relating to deaths that occur in disability accommodation services.

12. By way of suggestion, the writers contend that at a minimum the Committee should consider the following recommendations. That:

(i) All deaths are recorded as a singular category of incident.
(ii) A separate report entitled the ***Disability Death Report (DDR)*** is instituted and to be used for the reporting of each and every death.
(iii) In addition to notification of deaths to be made to the Coroner as required by law, the Department must ensure that an investigation of each death is undertaken.
(iv) In terms of the investigation of each death, the intent must be to determine as to whether the cause of death was related to neglect, abuse or violence.
(v) Depending on the outcomes of the investigation, appropriate action is then taken to ensure that if the death has occurred as a result of neglect, abuse or violence, either by an action or inaction of a person or persons responsible, then these matters are to be directed to the appropriate authority and appropriate consequence are enacted.

Concluding Comment

13. Given the significant role the Department of Human Services plays in relation to incident reports and their association with the reporting of deaths, the writers of this submission urge the Committee to call the Secretary of the Department to provide detailed figures relating to all deaths since 2010-11.

14. The information sought should also include details of:

- How many deaths were investigated?
- The outcomes of such investigations?
- If investigations were not undertaken in relation to particular deaths, why not?
- What, if any action has been taken to ensure a greater transparency in the reporting of deaths?

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End of Submission