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Australia: Official report covers up deaths of disabled children

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Ten intellectually and physically disabled children and teenagers died at the Mannix Children's Centre in the Sydney western suburb of Liverpool between July 1998 and October 2001. Their deaths were the direct product of a systematic run-down of facilities by both state and federal governments over the past two decades.

The children, aged between 8 and 19, comprised one quarter of the residents at Mannix. They suffered malnutrition, poor infection control and a lack of access to pain relief, all of which contributed to their deaths.

A state Labor government Community Services Commission report on eight of the children, released in February, accused the Mannix management of failing to meet its responsibilities. "Specifically, the service failed to adequately address the medical, health, developmental and physical needs of these eight children."

But, as the Intellectually and Physically Handicapped Childrens Association (IPHCA), which runs the home, explained in its response to the report, Mannix had suffered substantial government funding cuts, was unable to employ sufficient staff and could not obtain critically needed specialist help from the government's local Area Health Service. Not one of these factors was mentioned in the official report.

The eight children, all permanent residents, had spent most of their lives at Mannix. They suffered multiple and complex health problems, including cerebral palsy, epilepsy, spastic quadriplegia and severe intellectual disability. Seven had dysphagia (swallowing difficulties) and some had vision and hearing impairment.

Respiratory disease was the most common cause of death, with five instances of pneumonia. Other deaths were attributed to cardiac arrest, secondary chest infection, cerebral palsy and epilepsy. But, according to the official report, malnutrition hastened at least seven deaths. "The inadequate nutrition management appeared to be a major contributing factor to the overall poor health outcomes for the seven children and young people who were severely underweight and experiencing dysphagia."

The report found a failure to consistently monitor and follow-up individual nutritional needs for the children, four of whom were enterally (tube) fed. Growth and weight records were substandard for six children. One of the boys who died, at the age of 14, was not classified as malnourished, even though he weighed just 13 kg and showed virtually no weight gain in the last two years of his life. The youngest to die, an 8-year-old boy, weighed only 10 kg, yet staff failed to record his weight for a four-month period.

There were no immunisation records for seven of the eight children and other medical records were "very poor". One young girl had been treated throughout her entire 13-year residency with an anti-psychotic drug, but only one four-week period was recorded. In that period, staff signed the documentation twice a day, indicating the resident had been given the medication twice as often as prescribed.

Palliative care was fragmented, inconsistent and its referral ad hoc. Scant attention was paid to ensuring that residents were comfortable and without pain. "Six of the eight individuals experienced pain associated with their disabilities and their health conditions, yet access to pain management services was limited."

According to the report, Mannix provided no external training or formal supervision to the nursing staff for mealtime practices, enteral and other feeding techniques, correct positioning, diet preparation or dysphagia screening tools.

While condemning the Mannix management, the report admitted that conditions in the home were by no means unique. They represented "limitations in the broader system of disability services for children and young people. The issues identified are unlikely to be unique to Mannix, with similar problems having been identified in other services for children and young people with disabilities.”

Moreover, the report acknowledged that there were no standard competency requirements for staff caring for children and young people in residential disability facilities. “Both the skill levels and the training arrangements are determined at the discretion of the service provider,” it pointed out. This appalling state of affairs continues to affect 301 disabled children who remain in residential care throughout the state, an increase from 283 in 1999.

Only in 1998-9 did the Department of Aging, Disability and Home Care (DADHC) introduce guidelines for nutritionally adequate diets and safe food handling and provide strategies to better manage health risks associated with swallowing problems.

The Mannix tragedy is part of a much wider crisis. Some 4,500 disabled people live in residential institutions and group homes in NSW. Between 1991 and 1998, 211 died. An official review found that one in five of these victims was under 20 years of age. Respiratory disease was the cause of death in nearly half the cases and the rate of accidental deaths was twice that in the general population.

The government has cynically seized upon the Mannix report to threaten to close the centre within six months and accelerate its 12-year program of shutting down the larger care institutions and shifting residents into smaller group homes and family care arrangements. For high-care patients, this could impose an intolerable burden on families or nurses assigned to group homes. If institutions such as Mannix are unable to cope, what will happen in group homes, where supervision, nurse training and medical administration are even more limited?

Parents of the victims have decided not to comment publicly, but IPHCA said it failed to address three key areas—funding, resident/staff ratios and access to specialist care. IPHCA, which established Mannix in 1974, is a charitable organisation formed by parents seeking educational opportunities and long-term residential placement for their disabled children.

From 1974 to 1993, the federal government provided funding for centres such as Mannix, covering all staffing and administration costs. In 1993, however, the Keating Labor government shifted responsibility to the state government, which introduced “block funding”—the allocation of a fixed amount each year.

According to IPHCA, the shortfall between funding and costs was $99,083 in 2001, a deficit of $3,302 per resident. Mannix received $66,355 per resident, compared to average funding of $98,000 per resident in group homes. The shortfall had a direct impact on the levels of staffing and care, with the staff-resident ratio ranging from 1:3.3 in the morning to 1:10 at night. Improved staffing at meal times would “enable greater levels of support to residents who require intensive feeding and nutritional programs,” IPHCA emphasised.

IPHCA also pointed to the state government’s inadequate provision of public health services, claiming specialist help, including dietetic, speech pathology and staff training was not available from the local Area Health Service. “No assistance has been provided to the Mannix Centre in securing on-site specialist medical services, no guidelines exist for where a dispute arises to timely access to specialist medical services, and no liaison protocols with the Department of Health exist that can be used to negotiate regular medical specialist clinics on-site.”

Finally, IPHCA noted the lack of relevant state government guidelines: “The Mannix Centre was examined on clinical practice issues for which in some cases there were no policy or guidelines in the disability service system generally.”

Despite the official cover-up, the Mannix deaths highlight a glaring contradiction. Advances in medical science have created vastly improved survival rates for severely disabled babies. At the same time, they have opened up a whole range of possibilities for dealing with and overcoming disabilities—intensive physiotherapy, occupational therapy, and the development of communication skills. But instead of harnessing these innovations, governments are cutting back on already meagre services. The result is that, at the beginning of the 21st century, young children are dying painful, tormented and unnecessary deaths.