The well-worn path to systemic abuse of people with disability

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"Culture trumps regulation every time". Unknown.

Historically, the most common societal response to people with a disability has been outright killing or social exile[i]. Aristotle stated that "Let there be a law that no disabled child shall live" and Sparta had a policy of leaving children with a disability out in the weather to die. In the middle ages many mothers who had a child with a disability were accused of sleeping with the devil and executed. The people themselves were always on the margins of society and warehoused in 'cities of the damned' along with prostitutes, epileptics, paupers and others abandoned by society. These evolved into the huge institutions of the 18th and 19th century, with many continuing in until late last century and some even existing today. In the early part of the 20th century with the advent of Darwin's theory of 'survival of the fittest', the theory of eugenics was developed by Galton, a nephew of Charles Darwin. This had a huge impact across the western world with citizens joining eugenics societies and competitions held for 'the best-bred baby'. People with disability were seen as a moral and genetic threat to society with strong moves across the western world to segregate and sterilise them – particularly people with an intellectual disability. Leaders such as Churchill, Keynes, Huxley and many others spoke on the dangers of 'idiots, imbeciles and morons' as they were called, and the intelligence test was used to find them and separate them out. Families were encouraged to send their child to the institution for the good of the country. The eugenics idea was taken up by Hitler with the result that over 250,000 people with disability were murdered. The gas chambers were actually designed by doctors for the killing of people with disability and upscaled for the mass killings of other groups.

It was not until the beginning of the parent movement after the Second World War and the exposure of the horrific abuse in institutions in the 1960's by the Kennedy administration that the situation started to change. However, the model did not change. The 'new approach', the 'answer', was for people with a disability to be housed in small houses or hostels in the community. As has been well documented, the abuse has continued to the present day.

There are multiple lessons to be learned from this history. The idea of segregating and congregating people on the basis of their disability was not designed from noble motives of providing the best possible life opportunities. It was continuing a tradition going back centuries that people with a disability did not belong in society and in fact were a danger to it and should be kept together and apart. Almost every service providing segregated and congregated accommodation options will have a mission of community inclusion but the life outcomes indicate that this is a dream rarely experienced by people with an intellectual disability in particular. To segregate and congregate people with disability in order to teach them to be included in society is logically absurd.

Taking the particular example of education, initially people with a disability were denied any education, with the IQ test used to classify people as 'ineducable' (IQ below 50) or 'untrainable' (IQ below 30). In Western Australia this did not change in the law until 1979 – up to that point an individual with an IQ below 50 was denied education by law. Other States have a similar history. To label a group as ineducable clearly precludes them from sharing the same educational experiences as others. Instead they will be taught 'life skills', based on a curriculum developed by Edouard Seguin in the mid 19th Century to make 'idiots' productive members of the community.   The first schools were in the institutions and completely segregated, so as education was extended to people in group homes or living at home, it was a natural progression to similarly provide segregated and congregated education. That is, schools were not designed in that way on the basis of research or enlightened policy – in fact the research from the 1960's supported full inclusion as it does today.

The major lesson from the history of abuse with a whole range of groups is that in order to inflict systemic abuse, the class of people has to be devalued and seen as 'not like us': differently human, or even non-human[ii].   Once this has occurred it is possible to 'legitimately' reject a whole class or group of people and subject them to experiences that would not be acceptable to others who were not similarly devalued.   The obvious examples are segregation, lifetime congregation with others similarly devalued and 'branding' as having certain negative characteristics to justify the actions taken against them.   The negative roles can be 'animal-like'; 'vegetable'; 'menace'; 'eternal child'; 'object of pity and charity'; 'dying or as good as dead'; 'incapable of learning' and many others. A look at examples from around the world shows the use of such terminology as a gateway to horrific treatment.   Ethnic cleansing is typically preceded by labelling a class of people as 'cockroaches', 'rats', 'terrorists' or similar less than human characteristics. Labelling a group as 'objects of pity and charity' allows large scale removal of rights, lifetime separation and minimalist treatment 'for their own good' - as occurred with Aboriginals and the missions and still occurs through many disability agencies.

In providing any service to a group of people, valued or devalued, the process is underpinned by a range of assumptions.   These assumptions are often not explicit but are discernible from the service characteristics.   There are assumptions about the nature of the people served; their needs; what works; the appropriate 'staff' and training; the appropriate grouping and the appropriate activities. If we look at the apparent assumptions underpinning the institutional care of people with disability it is apparent that they included:
• They are not the same as other humans (we would not do this to valued people).
• They need to be segregated from others in society.
• They need to be congregated with others with disability.
• People need to be paid to share their life.

After seeing the horrific abuse that occurred in institutions, the reform movement set out to shut the institutions and move people into community accommodation where they would live in small group housing in the local neighbourhood and experience life in the community. Their quality of life showed significant improvements and indeed they do spend time at the local shops and experience community activities. However, the abuse continues and is often harder to police due to the isolation of the individuals. If we look at the underpinning assumptions of the group home model it is understandable why abuse is still occurring. The above assumptions of the institutions are identical for the group homes.

So what happens when we change the underpinning assumptions?
- We are all part of the human family with equal inherent value.
- People need to live with other valued people.
- People with disability should not be placed with others with disability except by their clear choice or an intimate relationship.
- People from the community will willingly and freely share their life.

In research conducted by Curtin, Sydney and Melbourne Universities under an Australian Research Council grant, an evaluation instrument was developed and it was applied to around 130 examples of supported living arrangements for people with significant disability[iii]. This study showed that with appropriate leadership, often by families but also some enlightened agencies, high quality living arrangements with real community engagement and good quality of life was being achieved and in many cases the individuals were living in genuine relationships with regular community members who were not employed as staff. These alternatives would not have been possible under the assumptions underpinning group homes and hostels.

The almost universal experience of systemic abuse is that it is preceded by a series of assumptions that characterise a group as non-human or lesser human, have needs that are different to others and so need to receive specialist services. This seems to inevitably progress to segregation and congregation with others similarly defined, imaging in devalued ways and procedures employed that would not be used with valued people. This is the start of systemic abuse, which opens the gateway to individual abuse as the organisations in charge have already shown that the people are to be treated as lesser, even though their policies will almost always say the opposite. We have a Royal Commission into aged care, a Royal Commission into the abuse of people with disability; we have had numerous reports on abuse in institutions; The Royal Commission into the abuse of children covered the abuse occurring in special schools; the history of mission treatment of Aboriginals has been widely commented on … The common characteristic of all of these is assumptions about the people not being the same as everyone else and needing to be treated together and apart. Until these fundamental issues are addressed, this culture will overwhelm regulation and recommendations for 'improvement'.

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[i] Bradock & Parish (2000). An institutional history of disability. University of Illinois. , and "As hort History of Disability https://www.youtube.com/watch?v=js2qgVhmH88

[ii] For a fuller analysis of the processes of devaluation see Wolfensberger, W. 1992. *A brief introduction to Social Role Valorization as a high order concept for structuring human services*. 2nd Ed. (revised Edition). Syracuse University, NY.

[iii] Cocks, E., Sorenson, S., O, Brien, P. & McVilly, P. 2017. Quality and outcomes of individual supported living arrangements for adults with intellectual and developmental disabilities: Final report. Curtin University Perth. https://espace.curtin.edu.au/bitstream/handle/20.500.11937/57936/Quality%20and%20Outcomes%20Final%20Report.pdf?sequence=2 See also Cocks etal. 2016. Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities, 20(2)*, 100-108. *Copy provided.*