SUBMISSION TO LEGISLATIVE COUNCIL INQUIRY INTO DISABILITY SERVICES IN TASMANIA

I present this submission on behalf of Tasmania's Polio Survivors. In 1937-38 Tasmania experienced the second highest per capita number of polio cases ever recorded world wide and this was followed by further polio epidemics during the 1940s and 50s up until the introduction of the Salk polio vaccine in 1956.

I contracted polio in 1952 and spent approximately two years away from home first in the Launceston General Hospital and then at St Giles Home for Crippled Children after which I returned home wearing callipers for a number of years. I was aged six years at the time and found it very difficult to fit in as family life had gone on without me for those two years.

However I did make what was considered a good recovery and on leaving school (The Hagley Farm School) at age of fifteen went home to work on the family farm. My main problems were poor co-ordination and general weakness particularly in the legs which prevented me from participating in sports etc.

I consider myself quite typical of the majority of polio survivors who have fought to fit in with society and tried to hide their disabilities as much as possible. We became very independent and fought hard to prove we were as good as anybody else and where possible self funded any treatment or special aids and equipment we needed.

In 1994 I underwent major surgery for an oesophageal hernia which went disastrously wrong resulting in a second operation to save my life but which also damaged my spleen, necessitating its removal, leaving me open to many infections since that time. The trauma of these events triggered the Late Effects of Polio (LEoP) which have severely adversely effected my whole life.

In 1998 I was instrumental in the formation of the Post Polio Network—Tasmania Inc. and held the position of honorary secretary until 2012 when I resigned in the interest of my own health and the organisation was wound up as no one else was prepared to take on that task. In 2007 I was involved in the establishment of the national body 'Polio Australia' and have represented Tasmania's polio survivors on that organisation since then attending many meetings, conferences etc.

As I was the contact person for polio survivors seeking help or advice and me being me I have continued providing a support and advisory service to Tasmania's polio community and am fortunate to have understanding GPs to consult with. I continue to compile and publish a forty page quarterly newsletter 'TAS POLIO NEWS' which is distributed by post to Tasmania's polio community and finds its way by email and post to interested persons throughout Australia, New Zealand and a number of other countries.

The introduction of the National Disability Insurance Scheme has been welcome by polio survivors in general but most of us find we are ineligible because of the cut off age of sixty five years. It is after that age that most of us start needing real assistance above what we can self fund as it is around that age the Late Effects of Polio (LEoP) really start to kick in.

We are continually told that the aged care system will provide for us but this is simply not the case as it not equipped to handle the difficulties of disability. The aged care sector seems to be able to assist in some very basic requirements but there is much inconsistency and unless you are lucky enough to be assessed by someone who understands the difficulties we face we are condemned to a life of pain and misery by being forced to use ill-fitting and inappropriate aids and equipment.

I am lucky to have inherited some aids and equipment from my now deceased parents and have been able to purchase a mobility scooter second hand but most polio survivors are not in that position.

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Having spent nearly forty years as a director of the St Giles Society I have also had access to many people with whom I can discuss my problems.

Over my seventy plus years I have unfortunately spend far too much time in hospital and the general lack of understanding of physical disabilities caused by polio and other illnesses is another major problem as nothing, or very little, appears to be taught in medical or nursing schools about these issues which leads to inappropriate care and treatment.

I have had the opportunity in the past to speak to a number of groups of medical students, nurses and carers but due to my increasing mobility issues I find that this is now too difficult.

As I see it the biggest problem is that while the official policies and guidelines are quite reasonable the availability of the services and equipment is very inconsistent in both the NDIS and Aged Care Sector. If you are lucky enough to be allocated an assessor who can understand the problems you face you may get all the assistance you could hope for but if you are not so lucky you miss out and there are many cases where some people are obtaining assistance far in excess of what they genuinely need whilst others with greater needs seem to go without even the most basic assistance.

Therefore the biggest problem to be overcome is the inconsistency in the use of available funds where the loudest voice gets the support and those that try the hardest and don't make a selfish fuss get ignored even though they are the ones who have contributed most to the community.

Arthur Lindsay Dobson.