Submission to the Productivity Commission on its inquiry into More Effective Social Services.

Introduction:

This submission is from NZORD, the New Zealand Organisation for Rare Disorders, a charitable trust set up in 2000 to represent the interests of those affected by rare disorders (prevalence less than 1 in 2,000). We seek to improve information, prevention, diagnosis, clinical care, community disability support, income support and research, for the benefit of patients with rare disorders and their families.

We do this because these individually rare disorders (about 7,000 of them) collectively impact on about 8% of the population, and many of them represent high levels of mortality, morbidity, and chronic health and disability among New Zealanders. They are high users and often very expensive users of health, disability support and social services.

We acknowledge up front the we have a generally good range of healthcare, disability support services, and other social services in New Zealand, with generally good access to them across most regions and health conditions. But it the gaps, the relative disadvantage and the disparities that are a significant problem for those with rare disorders, just are they are well known to be for certain other segments of the population.

The significant and achievable opportunities to improve health and disability outcomes, and reduce flow-on social service costs, are often missed because structural inertia means rare disorders are frequently, though not always, relatively neglected in our health and disability support systems.

Our submission is made at short notice. We apologise that it does not neatly fit the outline of questions you have posed. Our principle objective here is to emphasise the life-course needs and interconnection of health, disability support, and other social services, the need for a global view of the needs of this population, the opportunities lost, and the resulting costs, and the need for an action plan to address these issues. For those with rare disorders, such an approach is likely to be more effective in improving outcomes and avoiding mortality, morbidity and costs, than the specific questions asked about delivery, commissioning, etc.

NZORD would welcome the opportunity to meet with the Productivity Commission to discuss this submission and provide more background material and examples.

Key points of our submission:

1. Some high level changes to commissioning social services may possibly lead to improved outcomes across the health and disability sector and reduce resulting social services costs, but we believe this is not a given. In fact it may be a diversion from the core problems.

2. NZORD believes that the underlying philosophy and ideology that drives the existing delivery of these services is the critical aspect of efficiency/inefficiency and effectiveness/ineffectiveness of outcomes.

3. Many aspects of health service and disability support services delivery are unlikely to be changed for the better simply by change to who is the lead agency in the delivery of those services, or by changes to whether there is direct provision by government at Ministry or Department level, by its health agencies such as DHBs, or by Non-Government agencies.

4. Various Ministries and crown entities such as DHBs have a history of responding mainly to the politically driven Minister's priorities and in the context of tightly constrained budgets, have shown little motivation to seriously address "non-priority" areas such as the needs of those with rare disorders or their family carers. The relative neglect and lost opportunities remain unaddressed.

5. The history of NGO development in New Zealand, and of government contracting with them, is such that there is now considerable myth surrounding perceived ideals of innovation, creativity and efficiency in NGOs. Assumptions about gains possibly made by greater devolution to NGOs should be carefully weighed by the Commission. The myths may be especially real the longer they have existed and the larger they have become. However newer NGOs that are not deeply "embedded" in the system, may offer the sort of innovation, flexibility and fresh thinking the paper may assume is the hallmark of NGOs.

6. Government contracting processes and NGO "mission-creep" has resulted, since about the early 1990s in many instances, in the same underlying philosophy and styles of service applying whether the service is provided by government, crown entity, or NGO. The outcomes may not change at all, because of tight contracts and service specifications determined by an overarching philosophy and ideology that is resistant to innovation and change. This may be particularly so in disability support service provision.

7. The philosophy and ideology pursued by the Disability Services Directorate in the Ministry of Health in its Funded Family Care payments policy, is a particularly informative and most recent example. This policy is characterised by a significant lack of trust of families, an intensely rule-bound, suspicious and inflexible approach, and includes impossibly inappropriate provisions where the severely disabled adult child is the employer, usually of their mother. The extreme lengths to avoid any ongoing role or responsibility on the part of the Ministry and the intensely bureaucratic approach, can be contrasted with the scenario of non-funded family care where the Ministry and indeed society as a whole take no direct interest at all in the welfare of the disabled adult child, and trusts the family implicitly and completely in the care they provide. This example is compounded by the ideological capture by the disability theory that the disabled person should be "at the centre" of the policy, yet this simply and conveniently shifts the Ministry's responsibilities to a person who is almost certain to be unable to exercise them, and insults their family carer at the same time.

8. One possible impact of the commissioning/contracting/devolution of funding to NGO providers is the often discussed "underfunding" of the NGO sector generally. It is possible that the past low wage discussion about the sector, is now being overtaken by the "underpayment" scenarios of equal pay breaches and minimum wage breaches for those in paid employment, with similar issues paralleled in human rights breaches for non-payment of family carers, as the most significant outcomes from government moves in this area. Beyond the real and significant gain of shifting disability support out of institutions and into the community, other possibly beneficial outcomes are hard to identify.

9. For community advocacy groups, seeking incremental or even significant change within these social services through engaging with those responsible for them, is often a frustrating if not futile exercise because officials are mostly strongly wedded to the status quo. Their focus on political risk management, cautious budget management, extremely cautious approaches to any other risks, and their investment in the system as it is, leads to a lack of willingness or opportunity for creative and flexible approaches. It is clear that external forces, such as Ministerial direction, or recommendations from a body such as the Productivity Commission are needed to effect real change and drive effective outcomes. But note that regular external reports into disability support services, for example, seem to have resulted in no substantive change over a considerable period of time.

10. One aim of publicly funded research is to help lessen the incidence and health burden of disease and disability, and thus in turn reduce the overall burden on health, disability and other social services, including welfare benefits. In establishing their priorities for health research, Ministers and funding bodies such as the Health Research Council, in particular, seem blinded by a simple Pareto analysis that suggests the bulk of funds

should be invested in those conditions that take up the bulk of expenditure or affect the greatest numbers. This approach is valid in terms of public health outcomes such as reduction in smoking, achieving a healthy diet and exercise, and avoiding harmful exposures to reduce the onset of heart disease, cancer, respiratory disease, etc. The approach is wrong in respect of understanding the underlying biological and genetic drivers of disease. The counter-intuitive but correct analysis shows that much of what we now know about common diseases has been achieved by studying rare diseases. Future advances in the prevention, diagnosis, and treatment of common diseases, and the consequent reduction in demand on social services will come as a consequence of accelerating progress in the field of rare diseases, and research priorities should be adjusted to reflect this reality.

11. The collective impact of rare disorders has been recognised in various ways in other jurisdictions, especially the US, EU, Japan and Taiwan. In essence they have recognised that rare disorders are in fact a significant public health problem that requires organised efforts to address them. Public health policies and action plans are the principal approach adopted to address to needs of rare disorders. New Zealand needs a rare disease policy and action plan, as advocated by international rare disease organisations, to address the significant impact on social services that rare disorders represent. This is set out in the table at the end of this submission.

Other background discussion:

The focus of NZORD's submission is on the interconnectedness of the healthcare, disability support, carer support and income support aspects of social service delivery.

Those with rare disorders (including disease, syndromes, conditions, etc) are among the most vulnerable. There is relative neglect in prevention, diagnosis, clinical care and disability support for these disorders. Knowledge available to patients and families is harder to find. They are among the highest and most expensive users of health services. They are also very high users of community support, disability support and social welfare benefits, whether access via Ministry disability systems, DHB programmes, or income support via Work & Income.

Collectively, rare disorders represent about 8% of the entire population, covering all ages, but with most appearing in childhood and resulting in high mortality and morbidity. They represent a significant direct burden on the patient and their family, and often have significant economic impacts on families, including earning capacity, career choices, relocation needs, etc. This poses an economic burden on society as a whole, in addition to the more direct social service costs.

Recent research by NZORD (in preparation for publication) shows the actual spend from the health vote for 9 selected and broadly representative rare disorders, averages more than 7 times the Treasury estimates of average health care costs. We can discuss this work with you if you wish.

New Zealand can and should do better in how it responds to the whole "life-course" needs of rare disorders. This includes adopting best practice in primary prevention, screening, diagnosis, access to clinical care, disability support, education support, palliative care, income support, and community integration. While much of our health system is well organised and of a high standard, there are often areas where significant improvements can be achieved, and provision for the needs of rare disorders is certainly one of them.

Government provides billions of dollars in Working for Families support without detailed scrutiny of how the funds are used, and with minimal accountability. This contrasts with the intrusion and lack of trust ingrained in the provision of many health, disability and other social services. A significant rethink of philosophies and ideologies needs to occur.

Our failure to provide a systematic response to these needs constitute an affront to the right to health and the principle of universal health care. It also continues the ongoing imposition of avoidable health, disability and other social service costs.

Other developed nations have moved to recognise and respond to the needs of rare disorders with specific polices and action plans. New Zealand is failing to keep up with best practice by not addressing these issues in a systematic way.

Intervention is needed to stimulate action in this area because those who are responsible for the structure and implementation of the existing system, are also those who are wedded to its design and current philosophy. In addition, not being on a priority list means in effect, no action will be taken in most of these areas, and where some action is taken it is invariably very incremental and cautious with little significant impact.

The most recent literature on the value of research into rare disorders is the book *Rare Diseases and Orphan Drugs: Keys to Understanding and Treating the Common Diseases* by Jules J Berman. Dr Berman is highly qualified in cancer biology, informatics and computer programming. He is co-author of hundreds of scientific publications and this is his sixth book. It is available online at the Elsevier store. The arguments for the wider benefits to the whole population from rare disease research, are compelling, but our research funders do not see this reality, to the long term cost of those with common as well as rare disorders.

Our suggested action plan :

The adoption by the government of a rare diseases policy would ensure that the desired goals of prevention, early intervention, best care, and best support, will help towards goals of reduction in incidence, severity and costs. A suitable action plan that includes the following:

Areas of action	Details	Driving principles
Primary prevention	Ensure best antenatal care. Folic acid fortification of food. Preparing for life initiatives. Best practice antenatal and newborn screening. Better information for those at risk.	Reduce and minimise the incidence and severity of rare disorders.
Early and accurate diagnosis	Boost genetic and paediatric services capacity. Ensure adequate budgets for testing. Establish timeframes for diagnosis. Review access and funding for pre-implantation genetic diagnosis. Ensure screening from sequencing technology is implemented when clinically validated.	Early intervention saves lives and reduces costs. Test sooner with a lower threshold for action. Trust mum when she says “something seems wrong with my baby”.
Optimal clinical care	Establish national services where appropriate. Ensure cross-boundary access to clinical expertise. Strengthen clinical networks nationally. Establish an orphan drugs access scheme. Improve transition planning between child and adult services. Ensure palliative care provision for children.	Quality of care and access to care should be determined by need, not by where you live. Equitable care for those at significant disadvantage because of rarity. DHB silos and professional roles should not impede delivery of optimal care.
Improve social,	Urgently review carer payments policy.	Respect and trust those who

community and income support	Review respite care system. Aim to significantly reduce bureaucratic requirements of disability support systems.	care for disabled family members. Give real choice and flexibility in support systems such as carer support.
Recognise and include patient advocacy groups.	Support their role as sources of information and peer support for patients and families. Include advocacy groups in service design, policy and research priority advice.	Patient/family advocacy group can play a valuable role in assisting patients and informing policy. They should be financially supported to fill these roles.
Give an appropriate priority to research into rare disorders.	Analyse and review research funding criteria.	Rare disease research has much wider societal benefits. The solutions and the benefits are often counter-intuitive. Beneficial results can have exponential benefits beyond the disorder studied.

Conclusion:

The significant personal, family and societal burdens and costs of rare disorders can be better prevented or managed, but the solutions may differ from those that could solve problems for other groups. A focus on commissioning and purchasing may well bring improvements for a wide range of situations where social services are utilised, but the significant needs of rare disorders are unlikely to be significantly improved by those contemplated approaches.

Rare disorders need specific consideration and attention within their own paradigm.