Response to the
New Zealand Productivity Commission
October 2014
Issues Paper
More Effective Social Services

2 December 2014

Ralph Jones

Chief Executive

IHC Wellington

TABLE OF CONTENTS

1. INTRODUCTION

IHC's Mission Statement

IHC will advocate for the rights, inclusion and welfare of all people with an intellectual disability and support them to lead satisfying lives in the community

1.1 IHC New Zealand Incorporated (IHC) is a community-based organisation advocating for, and providing services to people with an intellectual disability and their families. We have a proud history which reaches back 65 years to a group of families who set up an association to lobby for a better deal for their children. IHC remains firmly committed to the values these early parents represented - the inclusion of all people with intellectual disabilities in their local communities.

1.2 We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as active citizens in the community, and to have support that meets their goals and aspirations.

1.3 IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families. IHC supports 1500 families with children who have an intellectual disability, provides support and training for 4000 adults in work places and helps more than 3500 people with disabilities to live in IHC houses and flats. We also provide a number of specialist services such as behaviour support and training.

1.4 IHC advocates for the rights of **all** people with an intellectual disability (estimated population 89,000, NZ Census Disability Survey 2013).

1.5 IHC welcomes the opportunity to respond to the New Zealand Productivity Commission October 2014 Issues paper "more effective social services". We see this as a unique opportunity to consider how IHC's commitments and concerns sit alongside other social services and in particular what arrangements in Government commissioning and purchasing might provide better outcomes for the intellectually disabled population and their families.

1.6 Most previous considerations/reviews of the quality and effectiveness of government funded support for people with intellectual disability and their families have been focused on one government agency funder and hence there has been limited opportunity and potential for the cross government consideration, plans and actions required to make a real and sustained difference in the lives of people who require additional support from others for economic and social wellbeing.

1.7 In respect of previous reviews of disability support funding arrangements (pricing and purchasing) there has been a failure to act on the outcomes of those reviews, resulting in little progress made to shift from the prevailing model of third party contracting through inequitably priced and over specified contracts.

1.8 We note that the Productivity Commission process is occurring alongside recent examination of New Zealand's implementation of the United Nations Convention on the Rights of Disabled Persons, increasing acceptance that commissioning and funding arrangements need to prioritise choice and flexibility for disabled people, families and providers and at a time when government are leading pilots and trials in disability support provision with limited evaluation of, or established indicators for success.

1.9 We anticipate that some of the issues raised by the Productivity Commission will not be resolved quickly or easily. The history of disability policy within New Zealand and internationally reflects a lack of agreement as to what are the reasonable costs that individual, families and communities might bear and what is the size and scope of government responsibility.

1.10 IHC notes the emphasis in the Issues paper on the role and history of the social welfare system and suggests that the notion of a social contract warrants further examination than the scope of the Issues paper allows. A narrow focus on more efficiency by commissioners and funders or demands of more money by individuals, families, community and providers will fail to address or resolve the complex relationships, transactional or otherwise, between the individual and the state.

1.11 We believe that a corresponding focus on what is required to support individuals with disability as active citizens and what is required to build responsive, capable, connected and inclusive communities is needed. It is critical that we understand the reciprocal and dynamic relationships between the active citizenship of disabled people, strong families and communities which are supported in their development through targeted investment. Outcomes from this investment will result in strong capable community organisations, good quality contracts and delivery of quality effective and efficient support to citizens in an equitable and sustained manner.

1.12 IHC notes that lack of emphasis or analysis on community development including the cost of developing and maintaining robust community organisations. Nor is there clarification on how political priorities or government structures influence or shape the social service landscape. Even with this additional information it is well recognised that productivity in social services is problematic to measure.

1.13 We note further that a strong social sector is inextricably linked to a strong public sector exhibiting leadership, expertise and capability to innovate and evaluate interventions. Recent downsizing and resource shifting across the public sector reduces confidence that the cross government agency ways of working required for effective social service delivery in a time of increased vulnerability and inequality will be achieved.

2. SUMMARY STATEMENTS

2.1 IHC believes that there are merits in an investment approach.Getting it right for an intellectually disabled population will deliver positive outcomes for them, their families and communities.

2.2 IHC believes there are constraints on how an investment approach might be applied to services for people with intellectual disability. We recognise however that segregated specialist care including residential care are likely to be inefficient compared to preventative and investment approaches hence the need for investment in disabled people and communities.

2.3 Investment approaches typically work well when a service can demonstrate it makes a difference and outcomes can be recorded. It is therefore imperative that government and community develop a better understanding of the links between different factors and outcomes for disabled people to enable fair and efficient investment. Clearly this will involve better data collection, linking and analysis.

2.4 Some of the key outcomes sought for people with intellectual disability are safety, security and inclusion and are more difficult to measure. The absence of good data across all aspects of the lives of people with intellectual disability hampers the development of robust outcomes indicators and future planning.

2.5 IHC believes there is scope on the margin for innovative models of commissioning and purchasing which would benefit the intellectual disability population across life stages and changing levels of support requirements. In addition we emphasise the importance of consulting directly with people with intellectual disability and their families about commissioning and purchasing arrangements. IHC reiterates the offer made verbally to the Commission to facilitate those opportunities.

2.6 Some of the services provided at the more specialist end of the service continuum might lend themselves to an investment approach e.g. mental health crisis respite and specialist behaviour support services which can avert the need for more custodial models of care.

2.7 IHC believes that for services for people with intellectual disability the principle investment logic is to intervene to keep things going well. This would require intervention at a different end of the service continuum and a rebalancing of resources to include greater levels of support to children and families.

2.8 Targeted investment in the early years of a child’s life so that the child and his /her family can access integrated, timely, quality, sustained and flexible support and services from mainstream/universal services and specialist services. The Whanau Ora approach of an integrated across government policy and funding framework at an early stage would result in fewer ongoing costs throughout life stages.

2.9 The current pattern of care has been driven by funding structures that came out of the maximization of the benefit to provide a care payment for people coming out of institutions. In the intervening period children have been going to school and young people have grown up in families. A sound investment approach would recognize this shift and direct more resources to supporting families in their role of primary caregivers.

2.10 An investment approach requires a move away from a government funded social service model which sees the individual and their needs as the problem, whose needs are met by providers and professionals to a model which builds and strengthens their relationships with each other, their family/whanau and community.

2.11 IHC believes there are strengths and weaknesses in the current approaches to commissioning and purchasing disability services and that there are lessons to be learnt from recent initiatives and approaches both in New Zealand and overseas**.**

2.12 The discussion and questions generated in the issues paper are more relevant to the provision and purchase of short-term interventions than to the design of an effective life-long support system.

2.13 The intellectual disability sector has not operated under competitive market conditions given that for many categories of services there are a limited number of providers, often only one in particular localities or specialties with few incentives for others to enter the market. Disabled people may have only one choice of provider due to location or NASC decisions about availability of places.

2.14 The Ministry of Health as the dominant purchaser of disability support services defines the purchase price which may not be realistic thus compromising provider sustainability and or constrain innovation and quality development.

2.15 IHC believes multi-year high trust contracts that focus on achieving particular outcomes for a specified group of people would be transformative for clients, families and providers.

2.16 IHC's experience with contracting include historic and ongoing difficulties with over specified contracts and retrospective fee for services arrangements which restrict the ability to innovate, respond to a crisis or invest in service and staff development. Compliance costs and the impact of third party (NASC) contracts has driven up demands, heightened consumer expectations and driven out provider innovation and flexibility.

2.17 IHC considers that the best design for long-term disability support would be a modification of the present arrangement:

- simple funding levels that reflect the different resource requirements associated with different levels of need

- capacity for providers to pool that funding to achieve the most effective and efficient use of resource
- capacity for providers to provide wage rates to recruit and retain staff and ensure the skill development required to deliver quality services in work environments which can be stressful and physically and emotionally demanding
- multi-year contracts inclusive of cost effectiveness data
- measurement and reporting on outcomes (as agreed by client, provider and funder).

2.18 Quality outcomes for disabled people from social service provision will also involve investment in new technologies that allow for greater independence and targeted assistance for disabled persons to find and maintain employment.

3. SOCIAL, ECONOMIC AND DEMOGRAPHIC FACTS AND TRENDS – THE INTELLECTUALLY DISABLED POPULATION

3.1 2013 census data reports that there are 89,000 New Zealanders living with intellectual disability. In contrast 2013 Ministry of Health data indicates that 19,590 people with intellectual disability receive funded disability supports.

3.2 The increased number of disabled people (now 1 in 4 in the general population) will create increased demand for disability specific and wider social services. Inclusive communities will require focus and attention on the built environment and public attitudes. The issues for the disabled population are not restricted to individual issues but are environmental, political and social issues.

3.3 Some interventions for people with intellectual disability are directed at enhancing skills that will lessen future dependence on support.

3.4 That said the majority of support is life-long, directed at ensuring people with intellectual disability can have “an ordinary life”. This involves life-long investment that will fluctuate with changing needs. The need for support will not be extinguished by addressing “the conditions” or alleviating adverse social circumstances.

3.5 Much of current service design is influenced by the features of a client group able to exercise voice and choice. There is little recognition of the support required to support people with intellectual disability to exercise choice as others do. Many people with intellectual disability rely on support or on their families to exercise their right to make decisions.

3.6 Service design and purchasing models that presume a generic ‘disability population’ invariably disadvantage people with intellectual disability.

3.7 Intellectual disability occurs randomly across population groups. People with intellectual disability and their families often rely more on government funded disability supports and income assistance than other groups and are therefore more likely to understand the weaknesses and long term impact of commissioning and purchasing arrangements. Increasingly disabled people and their families want a greater say in service design and delivery and the government structures and mechanisms which impact on the extent to which service provision restricts or enables an “ordinary life”.

3.8 The intellectual disability population group has not traditionally been of immediate interest to politicians and this is reflected in the injustice of arrangements put in place and the persistent disadvantage suffered as indicated in the scarce health and other well being data available. An example of these arrangements is the lack of access to “universal” health and education due to repetitive and different assessments across government agencies to access “specialist” support.

3.9 Recent research completed by the Donald Beasley Institute into the experiences of people with intellectual disability in the legal system identified life experiences in the sample group that were characterised by; 50% of respondents had been removed from the care of their parents; most had been bullied at school; they experienced low levels of literacy and numeracy; formed few lasting relationships; and few found meaningful employment. In addition it was found that half of the female participants had been sexually abused as had one third of the males.

3.10 The life-long nature of support sets up a different set of relationships between provider and consumer and needs to be reflected in a different set of relationships between purchaser and provider.

3.11 IHC believes providers are increasingly caught in a growing gap between the needs and aspirations of disabled people (voice dominated by the physically and sensory disabled community) and what the government purchases. There appears to be an increasingly rights based consumerist stance with individuals and or their families wanting to choose and receive high quality personalised services within strong partnership arrangements

3.12 The history of disability policy reflects a lack of agreement as to what are the reasonable costs that individuals and families might bear and what is the size and scope of government responsibility.

3.13 The so-called contributory model of purchase for vocational services for people with intellectual disability exacerbates the gap between what those people and their families are seeking by way of ongoing learning and development opportunities and what the government purchases. A contributory model of purchase is an unusual hybrid sitting as it does between grant based funding and purchasing by way of contract.

3.14 Many people with intellectual disability are, along with the wider population, living longer. Co-morbidity of dementia within the intellectual disability population is creating pressure on disability and aged care provision.

3.15 There is a trend of increasing numbers of children and young people with very high and complex needs. The complexity of individual situations has created pressures on single funding streams which do not "speak " to each other or respond appropriately to the range and level of supports needs across or within different settings.

3.16 Although it is difficult to get reliable data it is understood from Ministry of Health figures that significant numbers of people with high and complex needs and their family/whanau do not access government support, despite being eligible and having significant needs. The reasons for a lack of uptake are not known or understood but it is likely that factors such as difficulties with access, quality of available services, negative previous experiences will be in the mix. Clearly though the low uptake will have an impact on productivity more generally as there will be costs for family members and the wider economy.

4. FUNDING FROM NON GOVERNMENT SOURCES FOR PROVISION OF SOCIAL SERVICES

4.1 IHC has a relationship with people with intellectual disability and their families that goes back 65 years and is not solely prescribed by contracts.

4.2 Over that time IHC has built a significant network of donors, supporters and volunteers that allow the organisation to make a contribution in the sector entirely apart from any government contracts.

4.3 It has been the generosity of New Zealanders in supporting IHC's mission that has allowed the organisation to build a significant housing portfolio. That asset has been the springboard for IHC's ability to enter into a social housing partnership with government (Appendix 1)

4.4 It allows IHC to maintain an information resource that is freely available to families, caregivers, people with intellectual disability and staff irrespective of their IHC association.

4.5 IHC is unique in the intellectual disability sector as the only provider with a significant programme of charitable activities. The value of this public good is often not understood or respected by government officials who see the sector simply in terms of contractual relationships. This ignores the richness and complementary nature of the work an organisation like IHC is able to support.

5. NEW APPROACHES TO COMMISSIONING AND PURCHASING

5.1 IHC supports the commissioning and funding arrangements within the Whanau Ora approach and believes there is value in exploring whether this cross government integrated approach combined with high trust contracts and non government commissioning agents warrants further exploration for the disability sector. We note to date there is little information available about the effectiveness or measurable outcome data of this approach.

5.2 Individualised funding for disability supports services, person directed budgets, allows for people with disabilities who are able to manage a budget and direct how and what services (home based and community support services) they want. There is a strong case for expanding the range of services that can be incorporated in person directed budgets. Person directed budgets however are not for everyone and should not be seen as the panacea to the longstanding difficulties disabled people, their families and providers of support services have experienced for too long

5.3 The individualised funding approach is occurring alongside other government trials and schemes designed to create more choice and flexibility in the lives of disabled people. These include Enabling Good Lives, Choice in Community Living, Local Area Coordination, the Funded Family Care scheme and the use of the Self Assessment tool.

5.4 Although the initiatives to date appear attractive and align well with the choice, control and flexibility imperatives of the disability social and rights movement, there is considerable caution emerging relating to the lack of community lead approaches and the lack of sustainability given concerns about effective or efficient use of finite resources.

5.5 Currently initiatives are small scale, confined to small pilot projects and ad hoc. IHC has concern that the outcome of the evaluation of the pilot projects will not be widely shared particularly if they fail to deliver the expected outcomes.

5.6 The pilot projects have been designed for a generic disability population and may not meet the needs of people with intellectual disability. The individualised funding pilot for example assumes the ability of the client to exercise voice and control. In many cases families will be doing this on behalf of adults with intellectual disability. IHC is not confident that the principles of supported decision making are understood and applied. There is little or no recognition of the resource required for people with intellectual disability to be able to participate as decision makers in these models as required by obligations under Article 12 of the United Nations Convention on the Rights of Disabled Persons (UNCRDP).

5.7 Many families who act as decision makers or support decision making for their intellectually disabled family member are articulating “new initiative burn out” and extreme confusion relating to a lack of coherent information which describes the interlocking features across the new initiatives.

5.8 IHC notes with concern that service design and purchasing models that presume a generic ‘disability population’ invariably disadvantage people with intellectual disability.

5.9 Available data relating to the numbers of people with intellectual disability engaged with the range of Ministry of Health "new model" initiatives indicate that the numbers are small and below what was targeted.

People with an intellectual disability make up just over 65 % of 31,575 MOH DSS clients.		
Support Service Type	**Total Uptake**	**Uptake by people with intellectual disability**
Individualised Funding	2097	868 41%
Enhanced Individualised Funding	235	108 45%
Enabling Good Lives - Christchurch	23	10 43%
Local Area Coordination	115 - ongoing relationship	Not known
Choice in Community Living	101	Not known but predicted as within the range of 60 -70%
Supported Self Assessment	503	217 43%
Funded Family Care scheme	161	Number not known- but eligibility requires person will be assessed as having high or very high needs

*Figures extrapolated from Disability Support Services Client Demographic Report September 2013. IHC notes the difficulty in collecting accurate data.

5.10 There appears to be a lack of economic analysis using appropriate methodologies including how initiatives could be "scaled up" from a demonstration project to a national programme. In addition evaluations do not typically investigate why people who might be eligible don't opt in.

5.11 There are risks in introducing person directed budgets to an intellectual disability population many of whom are either unable or need support to exercise choice. Unless resources are available for proper supported decision making it is unlikely that services for adults with intellectual disability lend themselves to be person directed.

5.12 There are risks that person-directed budgets take a short-term view of meeting needs and fail to recognise the value of a long-term relationship that can respond to changing needs over time. There is also the suggestion that person directed budgets with the corresponding focus on the individual may be ineffective in creating wider social change.

5.13 Issues of workforce planning and provider investment in capacity and capability also arise in person directed budget holding arrangements. Equally there will be vulnerabilities for support workers, including scare opportunities for skill development, in private employment arrangements.

5.14 The types of service that are currently understood to lend themselves to person directed budgets tend to be clearly defined specific supports for services easily accessed from a wide support worker pool (Home Support). Only a small proportion of services to people with intellectual disability fit this description.

5.15 Services to support the administration of the Intellectual Disability Compulsory Care and Rehabilitation Act (IDCCR) are not suited to client directed budgets.

5.16 The international experience with person directed budgets is mixed. Simon Duffy in "Travelling Hopefully" (2013) describes best practice examples of person directed budgets resulting in people and families having full control of entitlement budgets, flexibility and innovation and increased community living and more efficient systems in place because of the removal of a 'wasteful infrastructure of brokers, planners or other professionals'. Significant problems are emerging however with reliance on complex assessment tools, a developing industry of 'valueless' personal planning experts, the lack of a appropriate legal framework to support decision making and needs assessments and care schemes eroding the natural support of family and community.

5.17 Other research from the United Kingdom points to the difficulties people experience with managing budgets, particularly in times of personal stress or changes in support needs (Baxter and Glendinning, 2013).

5.18 Western Australia uses a Disability Commission model for funding services as well as developing disability policy. The Disability Commission is a crown entity governed by a board. IHC endorses the suggestion from CCS Disability Action that there may be value in investigating crown entities, with a representative board as a way to develop policy and commission services. This arrangement could serve to reduce political risk while at the same time relieving some of the workload pressures on government departments. The Disability Commission model was recommended by the Parliamentary Inquiry into the Quality of Care in Service Provision (2008). The Disability Commission model is an example of devolved decision making with greater potential for immediate response to changing needs or crisis.

5.19 Person directed budgets need to be seen alongside other government and community initiatives which increase choice and control while at the same time building strength, resilience and connection in communities which are well supported with early, proactive and targeted investment.

5.20 Barriers to applying international experiences to New Zealand include;

- translating from a large population base to a relatively small dispersed population. Economics of scale may not be realized
- availability of suitably qualified and competent workforce
- absence of good information and evidence in which to base decisions
- cultural considerations flowing from New Zealand's obligations under the Treaty of Waitangi regarding partnership relationships with Maori.

6. CLIENT INFORMED POLICY AND SERVICE PROVISION

6.1 IHC has trialled many different arrangements at all levels of the organisation (from house meetings to governance advisory groups) to ensure the views of people with intellectual disability and their families are included in service delivery and design.

6.2 The skills required and the costs associated with listening to the voice of people across the spectrum of intellectual disability is not always recognised. Their voices are often silent when the traditional models of advisory groups, youth panels, service satisfaction surveys are used unless these arrangements are specifically tailored to people with an intellectual disability.

6.3 IHC also believes that all voices (clients, families and providers) need to be taken into account in the design and purchase of services.

6.4 IHC supports devolved decision making. Decisions to commit resources to respond to individuals or families in crisis are best made locally. Current contracting does not provide for a local crisis response to need.

6.5 New Zealand research (Roguski, 2013) identifies that disabled people find it hard to speak up about abuse in service provision because silencing, negation and collusion type behaviours amongst support staff or management. For this reason we support the Commission's view a mediated view through advocacy organisations or service providers may not be as reliable as direct 'client' information (page 43).

6.6 Abuse and neglect occur when people with an intellectual disability are vulnerable and isolated. Disabled adults are more vulnerable when they live alone. As "new models" of support are rolled out across New Zealand specific consideration needs to be given to ensure vulnerability is not increased by independent supported living arrangements.

7. DISABILITY SUPPORT SERVICE PROVISION

7.1 Changes to provision, commissioning and purchasing will not result in more effective, quality services if the persistent underfunding and underinvestment is not addressed. Wage rates in the intellectual disability sector have been progressively eroded to a point that skills levels have diminished and quality compromised.

7.2 Credible service integration requires a focus on outcomes for a defined population in addition to budget holding arrangements which offer flexibility for services to be delivered across a range of providers. A further challenge for disability service provision is to manage risk in a way that allows people choice and autonomy.

7.3 IHC's experience with contracting has formed our view that highly specified contracts restrict ability to innovate and that retrospective fee for service offers no capacity to respond to a crisis nor does it allow for proper investment in service. IHC is concerned that compliance costs have increased and there is a disproportionate level of monitoring on low value contracts. In addition we are aware of the impact of a third party (NASC) contracting has driven up demands, heightened consumer expectations and driven out provider innovation and flexibility.

7.4 IHC believes that the move to a government controlled process for individual needs assessment has limited the responsiveness and flexibility of disability services. When services are highly specified and people are assessed as to where they fit in a menu of pre-determined options the capacity of providers to respond to people's holistic needs, which will change over time, is diminished.

7.5 IHC believes dependency is unlikely to be a problem if the service is meeting individual needs. For people requiring life-time support continuity, quality and sustainability are likely to be as important drivers as diversity and choice.

7.6 IHC acknowledges the size of its government contracted business. IHC's commitment to people with an intellectual disability would remain unchanged whether or not the organisation held service contracts. So the question of dependence of government funding cannot be simply answered.

7.7 IHC is unaware of any evidence that contestability has produced enhanced quality or superior outcomes. Further there is little evidence that it has resulted in reduced costs in a market with limited staff pool and a finite list of clients.

7.8 IHC's experience is that contestability simply shifts the management of the business from one provider to another with a shift of staff and clients between providers along with associated increased administrative costs.

7.9 Features that support contestability include the capacity of clients to exercise choice, good information available about quality, the ability of providers to come and go freely, a clearly specified product and a mobile workforce. For most of the services for people with intellectual disability in most parts of New Zealand, apart from perhaps home support, the scope for contestability is limited by low numbers.

IHC believes that contestability works against co-operation and collaboration. We note that price is reported by the Ministry of Health to be the last factor taken into account in assessing RFP's. The effect is that decisions often appear to be made on "softer" less defensible grounds.

While IHC has had experience of both success and failure through the RFP process it remains sceptical as to the rigour of the process and the rationale for seeking a contestable tender in most instances. Better information and reporting on outcomes to enable benchmarking on key indicators would provide much greater transparency and potential to offer a clear rationale for entering into a contestable process.

7.10 IHC is currently exiting from a national Behaviour Support service. To date the transition has been characterised by a lack of transition planning for IHC's part in the transition, shifting timeframes, no contingency planning to accommodate shifting timeframes, a focus on funding withdrawal rather than impact on clients and little recognition of the ongoing costs to existing providers of managing a drawn out transition.

7.11 There is a risk that funding for outcomes makes invisible the significant variation in effort that may be directed to achieving that outcome. IHC believes that the best design for long-term disability support would be a modification of the present arrangement;

- simple funding levels that reflect the different resource requirements associated with different levels of need
- capacity for providers to pool that funding to achieve the most effective and efficient use of resource
- multi-year contracts
- reporting on outcomes (as agreed by client, provider and funder).

7.12 IHC believes that the best design for short-term (specific and sometimes intermittent) support is person directed budget holding.

8. TECHNOLOGY

8.1 IHC is concerned that there is inconsistent government guidance and direction with regards to the adoption for non-government organisations to utilise Cloud Based Services that are hosted offshore. These are services that support our service delivery objectives, productivity goals, and provide true value for money for organisations such as the IHC.

8.2 A lack of proactive direction, support and guidance has created a barrier to IHC adopting cloud based services to support the organisations productivity and change programme. Impediments are creating obstacles to achieving our objectives. We now understand why some organisations don't use these services and miss out in the opportunities for increased efficiency and collaboration. Decisions that we are making today may last 5 to 7 years due to the investment required. Clear government support for adopting new opportunities for productivity would undoubtedly improve the return on our investment.

8.3 What would help us is a consistent approach and clear guidance which will enable us to take advantage of these services to increase our productivity while at the same time build our ability to work productively with our customers and Government.

9. CASE STUDIES

9.1 Services for people with disabilities are identified by the Productivity Commission as one of four case studies to be developed to inform the inquiry into more effective social services. The Commission is particularly interested in learning about

- Integration of services commissioned be separate agencies with responsibilities to the same person
- The effectiveness of person-directed budget models
- Difficulties in gate-keeping for person-directed budgets
- Managing boundaries between services provided under person-directed budgets and those provided under other arrangements
- Difficulties for people in learning about and accessing an appropriate set of services.

9.2 Appendix 2 gives examples that illustrate some of the areas of interest indicated by the Commission. IHC would welcome the opportunity to expand on these and further contribute to the case study development.

10. CONCLUSION

Thank you for the opportunity to have input into the work of the New Zealand Productivity Commission. IHC has attempted to provide information to assist the Commission's considerations about the effectiveness of social service provision as it relates to the lives of people with intellectual disability and their families. We are keen to engage with the Productivity Commission process and offer any assistance which would be helpful.

Bibliography

Baxter,K.,& Glendinning,C. (2013). The role of emotions in the process of Making Choices about Welfare Services: The Experiences of Disabled people In England. *Social Policy and Society,* 439-450.

Duffy,S.(2013). Travelling Hopefully: Best practice in Self Directed Support: The Centre for Welfare Reform.

United Nations Convention on the Rights of Disabled Persons.(n.d.).

Disability Services Commission. (n.d.);http://www.disability.wa.gov.au

Ministry of Health. (2012). *Consultation on Paying Family Carers to provide Disability Support*.Wellington: Ministry of Health

New Zealand Productivity Commission. (2014). *More Effective Social Services. Issues Paper.*

Roguski,M. (2013). The Hidden Abuse of Disabled People in the Community;An Exploratory Study. Prepared for Tairawhiti Community Voice.

Social Services Committee Forty-eighth Parliament. (2008).*Inquiry into the Quality of Care of Service provision for People with Disabilities-Report of the Social Services Committee.*Parliament.

Statistics New Zealand. (2014).*Disability Survey 2013-All Tables*

Appendix 1

IHC Housing Provision & Funding History

1949-53: IHC was formed, with an initial focus on establishment of occupation centres for children living at home, as an alternative to institutional placement. The next priority was short stay homes for children (family respite), followed by permanent homes for children whose parents could no longer look after them. This resulted in some branches purchasing respite homes with donated funds. The first home provided was in Jellicoe St, Wanganui in 1950.

1954: IHC was given free use of the J A Duncan Polio Hospital in Silverstream, Upper Hutt and operated this as Kristina Home. It negotiated government funding to run it, resulting in a contract that enabled operational subsidies as well as capital subsidies (up to 50%) for short stay homes for children under 16 years. The Mental Health Act was passed in late 1954, and this allowed short stay homes, while not permitting permanent accommodation in the community. Branches set out to fundraise to take advantage of these opportunities.

1954: Christopher House, the first IHC-owned hostel, was opened in Hamilton. This provided short-stay accommodation for 12 children.

Circa 1960: Following lobbying from IHC and its own internal reviews, the government conceded that its past policy on institutionalisation had some shortcomings and that it would no longer hinder IHC from setting up alternative permanent community care accommodation. Development of government institutions continued, but tended to focus on needs of the more severely disabled. Institutional placements peaked at 1,900 in 1968.

1963: Government budget extended their 50% capital subsidy on short stay homes and occupational centres to also include acquisition of hostels. IHC branches got actively involved in fundraising to purchase hostels.

1964: IHC had 12 hostels in addition to 13 occupational centres and 11 schools. This was only enough to satisfy one third of the then known need, and plans were in place for £348,000 ($696,000) of capital expenditure over the next two years, 55% of which was to be sourced from fundraising, and 45% from government subsidies. The IHC Annual Appeal was initiated to help meet this ambitious fundraising target.

1969: IHC successfully lobbied for operational subsidies from government for doing the state’s work in providing care and accommodation. This was set at 50% of salaries for day care staff and $1.60 per day per bed in hostels for children. This enabled further services and further hostels to be financially viable. A new Mental Health Act 1969 enabled transfer of control of institutions to local hospital boards and enabled voluntary and short stay placements, which increased opportunities for use of the community care alternatives. In 1969, IHC provided 221 beds and was planning for 248 additional beds in new or extended hostels. It found it was struggling to meet demand and decided to press government to establish a “comprehensive, orderly, nationwide scheme” serving all people with intellectual disabilities – either by establishing services itself, or by helping IHC to do so. IHC saw its role including being a ‘watchdog’ over state provided services as well as a pioneer of better types of services.

1974/75: Government halted any further construction of psychiatric and psychopaedic hospitals. The Ministry of Health deinstitutionalisation programme began – called the Community Care Programme (CCP). This was a $ for $ subsidy and was only for capital expenditure – operational funding came later. IHC never reached the target of 485 beds – it ran out of operational funds first. The focus continued to be on building hostels. Some hostels were built and owned by hospital boards, and this stock was subsequently transferred to IHC at no cost (refer notes under 1981 below).

1980 approx: Hostels provided 761 beds. Funding was made available through Social Welfare for operational and capital support. This money was allocated for 525 further beds and 600 day placements. IHC was free to use the funding for capital expenditure at its discretion. Categories for this funding were:

- Rental subsidy.
- Repairs & maintenance subsidy.
- Acquisition subsidy.

1981: The Minister of Housing included IHC in the government-subsidised Pensioner Housing Programme. ($1m was spent on acquiring 28 Housing Corp pensioner-style units in 83/84).

A Price Waterhouse Report commissioned by government recommended that IHC should manage all resources used to provide IHC services – this resulted in subsequent transfer of ownership CCP-funded hostels from hospital boards to IHC.

Mid 1980's: IHC undertook a review of its philosophy and policy and sought to limit numbers living on a site in order to foster normalisation. The decision to have no more than 8 residents, and subsequently 6 residents, resulted in a move to sell hostels (typically about 20 beds) and acquire homes (typically 5 beds) in the community.

Housing Corporation capital funding was made available for these homes in the form of grants or low interest loan mortgages. Most of this was allocated as mortgages at between 3.5% and 7% interest. Grants were typically limited to $15,000 to $20,000 per home, and were abated (written off) by 4% per year.

Legacy grants were fully utilised for capital expenditure. Fundraising for capital grants was done separately from general fundraising to meet operating costs. The Annual Appeal and Calf Scheme were targeted at the latter. Likewise, IHC's share from Telethon proceeds.

In 1985 the Sutherland Self-Help Trust provided a grant of $750,000 for the Sutherland Landskills Programme. This enabled the purchase of rural properties, which provided an asset base for subsequent growth.

In 1986 a shared equity arrangement was made available based on 'licence to occupy" concept used in rest homes. This was developed into the IHC Shared Home Ownership Scheme, which was launched in 1991 and attracted deposits of $2.6 million by end of 1997, involving over 200 investors. Depositors were mainly family of people with intellectual disabilities.

1988-90: Peak period for property acquisitions:

77 properties in 1988

133 properties in 1989

78 properties in 1990

Housing Corporation funds received – Emergency Housing Programme (primarily loans):

$13.5 million in 1988/89

$15.0 million in 1989/90

This period of growth resulted in beds in homes for over 2,800 people with intellectual disabilities, but also strained the financial viability of IHC.

1990: The country went through a period of economic hardship and the above government capital funding arrangements were discontinued. A previous Labour government commitment of $8 million of additional salary subsidies was not actioned prior to their loss of office. This placed IHC into a financial crisis. IHC got legal representation on the issue, and managed to secure agreement with the new National government for a $10 million loan that was interest free over a 10 year period.

No government capital or further loan funding has been made available over the 20 years since, other than a small amount available through Ministry of Health to aid Timata Hou RIDSAS set-up (2002) and establishment of restrained care facilities (2009).

1996: IHC purchased 293 mortgages from Housing New Zealand Corporation for $31.7 million and set up IHC Mortgages Ltd as a loan facility, and an agreement was reached with Trust Bank for advances of up to $40 million, of which $32 million was immediately drawn to settle the Housing NZ mortgage purchases. In addition there was a $7 million term loan provided by Bank of New Zealand.

1998: IHC property ownership and management was financially ring-fenced, with market rentals charged for use of housing by IHC support service operations. A small, professional property management team was engaged to manage the society's property assets in a financially self-sustaining manner.

The focus shifts to making existing housing better suited to the long term needs of people with disabilities and to replacing stock with high maintenance liabilities. There is slow growth in housing numbers.

2002 The IHC Shared Home Ownership Scheme was closed to new investors, and alternative shared equity arrangements offered, including unit titles, shared titles and a more conventional licence to occupy arrangement aligning with retirement home norms.

2010: Accessible Properties New Zealand Ltd was established to provide property management services to community organisations and to IHC. It is a fully-owned subsidiary of IHC New Zealand Inc. Ownership of the IHC housing portfolio remains with the parent organisation, and it is envisaged that community housing used outside of IHC will subsequently be able to be owned by Accessible Properties.

Andrew Wilson

November 2014

Sources:

Our History (1988) – IHC - based on a thesis by Alison Riseborough (1986).

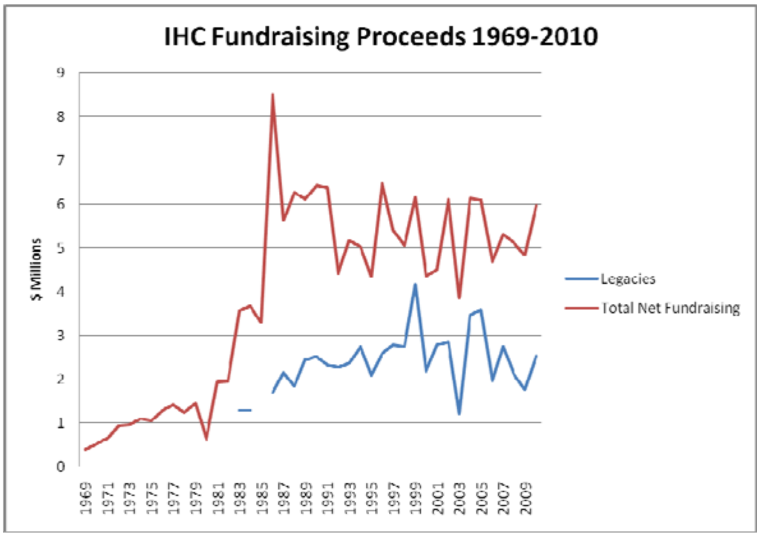
Breaking Barriers – IHC's first 50 years – Julia Millen (1999) – IHC

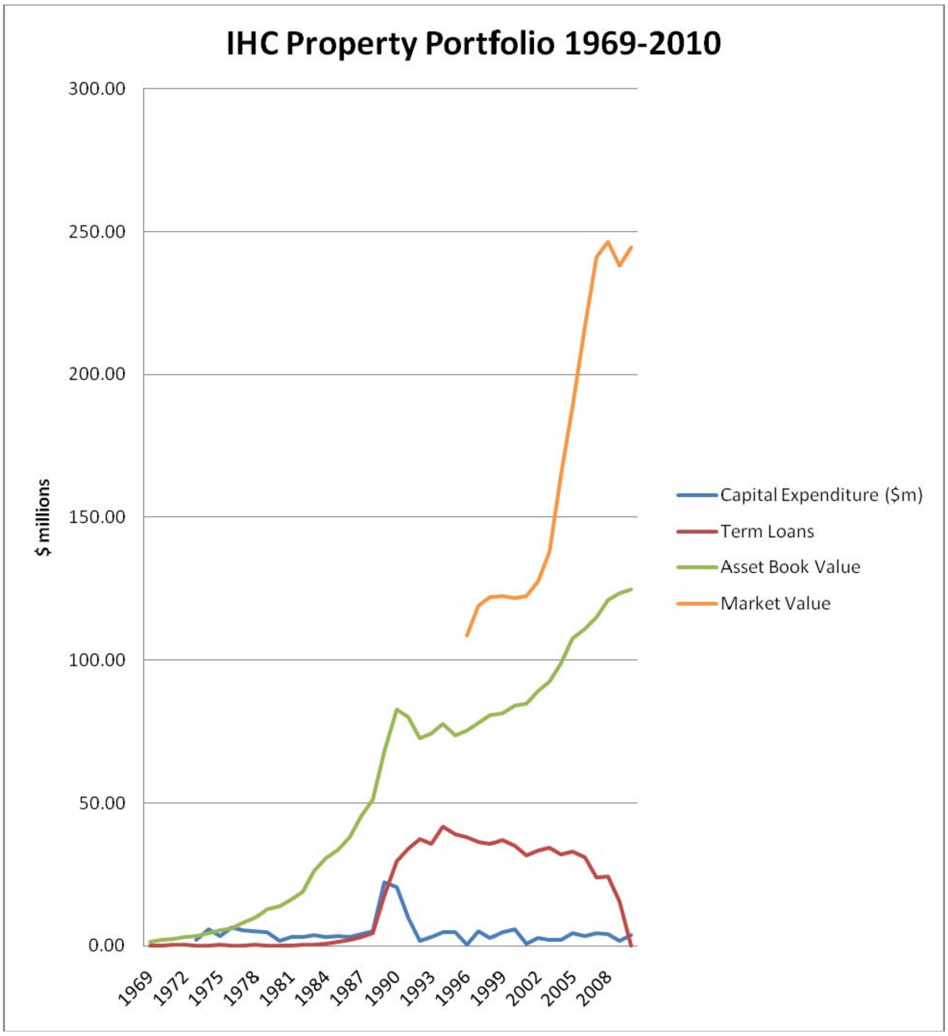
IHC 1970's-1990's – retirement speech notes made by Doug Bullen (Feb 1999)

Community Moves – 50th Year Commemorative Issue – IHC (Vol 36, No. 3, October 1999)

IHC Annual Reports from 1969 to present.

Discussions with JB Munro, Dr Roderick Dean, and Jan Dowland.




IHC Property Portfolio 1969-2010
$ millions
300.00
250.00
200.00
150.00
100.00
50.00
0.00
1969
1972
1975
1978
1981
1984
1987
1990
1993
1996
1999
2002
2005
2008
Capital Expenditure ($m)
Term Loans
Asset Book Value
Market Value

Case study examples

1. Difficulties in learning about and accessing appropriate services, integration of services commissioned by separate agencies and difficulties in gate-keeping eligibility

Ben is 7 years old and has Down syndrome. His parents Marion and Paul left the hospital after Ben's birth with his diagnosis of Down syndrome but no other information. With no extended family living close by Marion and Paul felt isolated and were concerned that they were not doing enough for Ben. None of the health professionals they encountered in Ben's first two years were helpful in knowing about and linking the family to community supports and information.

At the age of two Ben started going to an early childhood education centre (ECE) three mornings a week. Staff at the centre gave contact Marion and Paul details for parent and community groups. They followed these up and found talking with other parents and being able to access the right information extremely helpful. They continue to use these networks for support and also help other parents.

Ben's ECE teachers suggested that he be referred to the DHB Child Development Team (CDT). A practitioner from the CDT worked with Ben, his parents and the ECE staff to make adaptations to help Ben learn and participate with the other children at the centre. Marion and Paul were also able to use some of these approaches with Ben at home. Ben made great progress in his preschool years particularly in his communication and self care skills. In his last year at the ECE centre he was attending 20 hours a week.

Ben's experiences at school to date, however, have been very different. Ben's parents wanted him to go the same local school as his older sister, Rosie. Initially the school was unwelcoming. The school principal tried to dissuade them from enrolling Ben and suggested that a special school would be a better option for him. Marion and Paul did not want Ben to go to a special school as it would mean an hour and a half travel each day so they persisted until the school agreed to enroll Ben.

Despite the ECE centre offering to help the school with Ben's transition the school would not engage with his ECE teachers. As a result when Ben started school his classroom teacher did not have the benefit of knowing Ben and what worked well for him. Much time was spent putting an application to the Ministry of Education for Ongoing Resourcing Scheme (ORS) funding which was turned down. The reason given for declining the application was that Ben did not meet the eligibility criteria.

Currently Ben's school day finishes at 1pm three days a week as these are the times the principal has said that they do not have the "resources" to meet his needs. Ben's communication and self care skills have deteriorated and he has developed some "behaviour" problems at school. The school has made referrals for speech language therapy and an educational psychologist. Ben is on the waiting list for both and it is expected to be some months before he is seen. The school is saying they are finding Ben disruptive in class and too difficult to manage. The principal has said that they may have to cut Ben's hours at school even further than his three days of early finishes rather than Ben being attending school fulltime as had been previously agreed. Marion had been planning to work more hours but is unable to do so with Ben's current school situation.

2. Difficulties with gate-keeping eligibility for person directed budgets

Marama is a sole parent of three children, one of whom has a disability. All three children attend the local primary school and the after school care programme and Marama is really pleased she has been able to get off the benefit and get back to work.

Marama receives carer support to have the occasional break from caring for Becky her disabled daughter. Marama finds the rules around carer support really difficult. "The rules say you cannot use carer support to pay for child care while you are working. It would be great to use carer support funding to pay for the additional support Becky needs at the holiday programme for activities such as swimming. Sometimes my whanau would be better off on the benefit instead of trying to juggle and manage all the paperwork and rules around Becky's support. We just want to make our own decisions about what works best for us".

3. Lack of integration of services commissioned by separate agencies with responsibilities to the same person

James has an intellectual disability and autism spectrum disorder (ASD). The school principal made a report that James may have been harmed by his family. Child Youth and Family service (CYF) became involved and despite the parents' statements that they would harm him they refused to take any legal protective action on the grounds that there were no care and protection issues. James was placed in an emergency mental health forensic unit where he was considered to be inappropriately placed. The unit agreed to develop a specialised one to one respite service in the local community. Specialist and respite staff agreed that James could over time be placed back at his local school and live in a foster home in the one to one respite service.

A proposal was submitted to CYF who were advised that it was unlikely that the agency would agree to enter into a section 141 agreement in light of the parents' unwillingness to engage. The cost of the proposed one to one respite service was cheaper than the residential and out of community option on the table. CYF insisted this was not a care and protection issue. While waiting for approval to provide the one to one service, the Ministry of Health (MOH) agreed to fund a section 141 agreement for the parents to pass custody to a residential provider. James was moved out of his home community into a residential service. It is not clear whether CYF and the MOH ever communicated about this or whether the MOH were aware of the proposal for a placement in the local community.

The lack of agency integration resulted in James being moved from his home, school and community with his parents permanently losing custody of their child. James was placed into a more expensive option than that proposed by experts on the ground working with James

4. Lack of integration of services commissioned by separate agencies with responsibilities to the same person

Brian is 15 and has an intellectual disability and autism. He was enrolled at his local secondary school. Brian has behaviours that challenge at home and at school. MOH - Disability Support Services funded behavioural support services that worked successfully with Brian and his family to develop strategies to manage his behaviours.

Special Education staff had worked with Brian and the school staff to manage his behaviours at school. This had not been successful and incidents of challenging behaviour were increasing. The school called a meeting and asked Brian's parents to remove him from the school because they could no longer manage his behaviours.

Brian's parents suggested the school utilise the expertise of the behaviour support service they are using successfully at home. The school and Group Special Education Service staff said they could not do this. Brian's parents removed him and enrolled him at another school. This was extremely disruptive to Brian and resulted in increased education costs.

Brian’s needs were not at the centre of the decision making process. The lack of integration and consistency was confusing for him and his family. It was an example of costly, inefficient service delivery as both Brian and his family were working with multiple assessment and service delivery agencies.

5. Difficulties for people learning about and accessing an appropriate set of services

Ella is a 20 and has Down syndrome and autism. Ella was attending her local secondary school. She has developed a very complex health condition which has meant numerous hospital stays in the past 12 months. Her health condition means she defecates frequently and unexpectedly. This has been very distressing and unpleasant for her and her family. Ella’s school contacted her parents and suggested that her poor attendance was “blocking a place” in the special needs unit and asked that she leave school. The school did not offer or provide any education support for home or when she was in hospital or transition support to vocational or day services.

Ella’s mother gave up work and has struggled at home to support her daughter. The Needs Assessment and Service Coordination Agency (NASC) provided some hours of disability support. Lack of support for Ella’s health needs has meant that some of her allocated disability supports have been unable to be utilised, for example carer support or respite and she has not been able to attend day or vocational services as she has become so traumatised by her health condition and is fearful of going out because of her “accidents”. Ella and her family have become increasingly stressed and isolated as they struggle to manage at home.

Ella’s mother reached out in desperation to an advocacy organisation that raised the issue with others and subsequently learnt of the services provided by Care Coordination Centres. Advocates suggested to the NASC that they reassess Ella and make referrals to ensure both her disability, health and education transition needs alongside the anxiety that has developed as a result of her trauma were supported in a coordinated way.

6. Difficulties with gate-keeping eligibility for person directed budgets

Marjorie is 55 years old and has an intellectual disability and increasingly frail health associated with her aging. Marjorie lives with her retired brother Max, and his wife Beverley. She has done so for many years since her parents became too elderly to care for her.

Marjorie requires support for most things such as getting dressed, washed, meals and eating. Because Marjorie is prone to wandering she requires either Max or Beverley to keep an eye on her during the day. Funded Family Care is allocated for help with showering and feeding and tasks that are additional to the normal activities of the household for example additional washing due to incontinence. Marjorie is eligible for Funded Family Care as she has high needs.

Max had to be declared Marjorie's advocate so Marjorie could employ Beverly as the rules require. Twenty hours support per week has been allocated by the NASC. Max and Beverley think that the significant role they play in Marjorie's life is undervalued and unrecognised. They thought that having Max become Beverley's employer is ridiculous. Max said "I don't understand why they designed a system that is so hard, we felt like we had to tap dance around the rules to get any money at all. I know it would cost the government thousands to support Marjorie in a residential service. It doesn't make sense, we don't want to make money and we love Marjorie. She is so happy here it would break her heart to leave, but what Beverley gets paid is an insult for all the work we both do".

7. Integration of services commissioned by separate agencies, difficulties in gate-keeping eligibility, and managing boundaries between services

Helen is 64 years old and has an intellectual disability. She has lived in residential services since she was 26 and for the last 20 years has lived with three other people who are good friends. Helen's parents have both died. Her younger brother John and his wife Sarah live nearby and Helen frequently spends time with them. Helen works two mornings a week at an office, attends art and craft classes at the local community centre and volunteers at a charity shop.

Helen's mobility is not as good as it was and she needs a greater level of support than previously to manage her health and personal care. Helen wishes to stay living in her home with her friends, close to her brother and sister-in-law and in the community she knows as long as possible. Her residential service provider wants to support her to 'age in place' and have asked the NASC to look at ways to fund the additional support needed. The NASC have said they can't do this and Helen will have to move to a house that provides a higher level of care. The NASC has even suggested a rest home placement some distance away. The lack of collaboration between disability support, personal health services and aged care services and disputes about who should fund what adds a further barrier to achieving a solution that will allow Helen to stay living in her home.