



Submission to the Welfare Expert Advisory Group 2018

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1. Introduction

IHC welcomes the opportunity to contribute to the work of the Welfare Expert Advisory Group (WEAG).

We strongly support the creation of a welfare system that is accessible and fair for all New Zealanders. This submission sets out the changes we believe need to be made for people with intellectual disabilities and their families to:

- have an adequate income and standard of living
- be treated with and live in dignity
- be able to participate meaningfully in their communities.

Recommendations

IHC recommends:

1. Care is taken with how welfare reform proposals are framed to ensure the welfare system, and the social contract on which it is based, is inclusive.
2. The focus on earning, learning, volunteering and caring be broadened to include all contributions to a better future for all New Zealanders.
3. Human rights underpin the welfare system to encourage a flexible, respectful and participatory approach to determining what levels of support are needed to ensure an adequate standard of living.¹
4. A universal income exemption for people on the SLP and/or increasing the amount that people can earn before abatement rates.
5. Increase in earnings other than benefit payments not affect the accommodation supplement.
6. Benefit payments be indexed to keep them in line with inflation.
7. Policies, processes and practices within the welfare system recognise the right of people with intellectual disability to have information in accessible formats and to have support to make decisions.
8. The welfare system is linked to other government systems and policy settings so that people with intellectual disability and their families can expect an integrated and accessible response to their circumstances.
9. The principles underpinning the welfare system are consistent with, and support, Enabling Good Lives (EGL) principles.
10. The WEAG support the United Nations Committee on the Rights of the Child recommendation that the New Zealand Government adopt a comprehensive, child rights and participatory approach to the fulfilment of the rights of children with disabilities and ensure that the welfare system responds to the numbers of disabled children living in poverty.²
11. As a minimum, the welfare system should be consistent with the general principles of children's rights and;
 - apply without discrimination to all children³
 - ensure the best interests of the child is a primary consideration in all decision-making
 - support, to the maximum extent possible, the survival and development of the child
 - take into account the views of the child.

¹ See UNCROC articles 27, 2, 3, 4, 5, 6, and 12; UNCRPD article 28

² CRC/C/NZL/CO/5 Committee on the Rights of the Child *Concluding observations on the fifth periodic report of New Zealand*. Paragraph 30.

³ It should be noted that New Zealand has a reservation to the Children's Convention that means it does not have to be applied to children unlawfully in New Zealand.

12. The welfare system be flexible enough to provide a level of support commensurate with the reality of the lives of children with disability, based on research evidence as well as the views, experiences and circumstances of individual children and families.
13. The welfare system enable access to universal services and other supports, not create additional barriers.
14. Benefit sanctions affecting families with children need to be abolished immediately.

2. About IHC

IHC advocates for the rights, inclusion and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare and inclusion of all people with an intellectual disability throughout their lives.

We support people with intellectual disability to lead satisfying lives and have a genuine place in the community as citizens. We believe that the foundations for inclusion of people with intellectual disability in society are built on integrated support to families of children with intellectual disability.

Underpinning our work is the principle that intellectually disabled children and young people are part of the community of all children and young people – they are entitled to full enjoyment of their human rights and fundamental freedoms on an equal basis with other children and young people⁴.

3. Background information about people with intellectual disability

By definition, intellectual disability and the associated need for support to enable participation and inclusion are life-long.

There are more than 90,000 people with an intellectual disability or autism in New Zealand. Across all ages, many people with intellectual disabilities live in the most socioeconomically deprived households.

Life expectancy is alarmingly lower for people with intellectual disabilities – females over 25 years lower than average and males over 20 years lower than average.

Nearly 98% of the 2,320 people supported by IDEA (IHC's service arm) who live in Ministry of Health funded residential care receive the full Supported Living Payment (SLP) or NZ Superannuation (approximately 353 people receive NZ Superannuation). The remaining small percent receive either a reduced SLP or are not on the SLP, mainly due to working and earning above the threshold allowable to receive the full benefit.

Forty-two per cent of young people with disabilities aged 15-24 are not in employment, education or training.⁵ This is four times the rate of their non-disabled peers.

⁴ United Nations Convention on the Rights of Persons with Disabilities and United Nations Convention on the Rights of the Child

⁵ NZ Household Labourforce Survey 2017 – June quarter

For the quarter to end June 2018 there were 380 people living in IDEA's residential services who were in paid employment with the same rights and conditions as other workers. Of those 380, 70% of them worked an average of less than 15 hours per week.

Similar figures would be found for people living more independently, who live with their family or are supported by other service providers.

Children with disability are more likely to live in low income families. Data from the 2013 Disability Survey (the latest available) shows:

- 34 % of disabled children living in families that earn under \$50,000 a year, compared to only 24 % of non-disabled children.
- an estimated 17% of carers of children with disability were unemployed.
- 30% of disabled children lived in one parent households, compared to 17% of non-disabled children.

Estimates from the 2013 Disability Survey also suggest that children with disability were less likely, in the previous four weeks, than non-disabled children to have had music, art, or other similar lessons; played a team sport; done other physical activity such as swimming or gymnastics; visited friends; or been away on holiday in the past 12 months.

4. Dignity and earning, learning, caring or volunteering

*Inequalities in how society treats and values people, and the perceived status that people have, influence physical and mental health. Effort to reduce structural barriers that cause discrimination and negative impacts on lives should therefore be a priority concern for government policy. A well governed and compassionate society values and supports all its citizens.*⁶

Care needs to be taken with how any welfare reform proposals are framed to ensure the welfare system, and the social contract on which it is based, is inclusive, truly respects the dignity and contributions of all people, and guards against the "soft bigotry of low expectations"⁷.

We have some concerns about the emphasis in the WEAG documents on earning, learning, caring or volunteering as the basis for participation in the welfare system. Under paragraph 3 of the WEAG's terms of reference, the welfare system is to be "...part of an integrated Government approach that enables people to be earning, learning, caring or volunteering and ensures a dignified life for those for whom these options are not possible" (emphasis added). The introduction to the on-line submission says that the welfare system should treat people more fairly "... and also encourage them to be earning, learning, caring or volunteering, thereby ensuring a better future for all New Zealanders", which suggests those who are not earning, learning, caring or volunteering are not part of ensuring a better future for all New Zealanders.

There are many ways that people contribute to broader societal wellbeing and everyone is entitled to income support when needed. A limited focus on earning, learning, caring or volunteering risks marginalisation of people with intellectual disabilities, amongst others, from the outset.

⁶ Wendy Rickard and Angela Donkin "A fair, supportive society summary report; A social determinants of health approach to improving the lives and health of people with learning disabilities." Page 11

⁷ Phrase credited to Michael Gerson, speechwriter for George W Bush.

Emphasising earning, learning, caring or volunteering also re-enforces the message that not all contributions or types and amount of work are equally valued. Currently, under the welfare system, people are classified as to who:

- Can work more or less than 15 hours a week
- Are considered to have the capacity to work or who are permanently unable to work
- Are in the highly valued group of those who will have the most effort put in by MSD as they will get sufficient paid employment to no longer need a benefit

The welfare system needs to recognise and support a wider range of ways for people to contribute through paid and unpaid work, in open employment, micro and social enterprises, cooperatives, self-employment and volunteering, as well as through wider contributions such as, for example, the arts, providing friendship and support to others and actively participating in their communities.

A charity model of welfare that creates categories of deserving and undeserving poor should also be avoided.

A human rights-based approach to the welfare system would encourage a flexible, respectful and participatory approach to determining what levels of support are needed to ensure an adequate standard of living.⁸

Recommendations

1. Care is taken with how welfare reform proposals are framed to ensure the welfare system, and the social contract on which it is based, is inclusive.
2. The focus on earning, learning, volunteering and caring be broadened to include all contributions to a better future for all New Zealanders.
3. Human rights underpin the welfare system to encourage a flexible, respectful and participatory approach to determining what levels of support are needed to ensure an adequate standard of living.

5. People with intellectual disabilities and work

People with intellectual disability have among the lowest participation rates in the workforce of any population group in New Zealand.

Successful removal of barriers to work for people with disabilities requires Government to work in collaboration with disabled people and their families and service providers to genuinely co-design, implement and review opportunities for work. Consideration also needs to be given to creating a wider range of pre-employment and internship opportunities for young people with planning beginning during secondary school as with non-disabled peers.

Work environment-related factors in obtaining and maintaining work for people with intellectual disabilities include

- *Employers decisions and opinions* - concerns about safety, productivity and attendance which most employers concede can be mitigated by having the right support systems in place. Employers found employees with intellectual disability to be highly motivated and eager to learn and the culture in their businesses strengthened by dismantling of stereotypes and biases

⁸ See UNCROC articles 27, 2, 3, 4, 5, 6, and 12; UNCRPD article 28

- *Job content, requirements and performances* – there is a concentration of jobs in certain areas such as food and cleaning. While these are valuable jobs they don't necessarily represent the potential of employees or lead to career development. To address these issues training and support is essential for employers as well as employees.
- *Interaction and workplace culture* – these referred to interactions, inclusion, social support and participation that were identified as relevant aspects for obtaining and maintaining work. The best employers created opportunities for all employees to collaborate with each other, promoted flexible working arrangements, implemented diversity practices and team-building activities so social inclusion was nurtured.
- *Support by job coaches* – this covers the support provided by employment services and supported employment providers for employers and employees in finding and setting up work, structuring the work day, establishing routines, suggestions for adaptations and accommodations and education with co-workers on how best to communicate with colleagues. People in these roles also provided help with some of the difficulties that may arise such as not being able to read or write, interpersonal conflicts as a result of mis-reading social cues, or transport issues.⁹

6. Abatement rates and eligibility thresholds

One of the biggest barriers to people with intellectual disability taking up more hours of paid work is the fear that they will be worse off financially and lose their entitlement to the SLP. The welfare system needs to better respond to fluctuating income from part-time and casual work to remove barriers and address people's fears about the impact of hours of work on their income.

In addition some abatement and eligibility thresholds are still at the same levels they were 20 to 30 years ago contributing to the disincentive to people trying to find work. The more people earn the more people lose resulting in small returns that and can leave people out of pocket, especially if they are paying for additional expenses such as transport to and from work.

People with intellectual disability are also concerned about the impact on the accommodation supplement of an increase in non-benefit income as well as the need for benefits to keep pace with inflation.

Recommendations

7. A universal income exemption for people on the SLP and/or increasing the amount that people can earn before abatement rates.
8. Increase in earnings other than benefit payments not affect the accommodation supplement.
9. Benefit payments be indexed to keep them in line with inflation.

7. Interacting with the welfare system

Reasonable accommodations are needed to enable people with intellectual disabilities and their families to interact with the welfare system. For example, providing information in

⁹ J. Ellenkamp, E. Brouwers, P. Embregts, et al. (2016). Work environment-related factors in obtaining and maintaining work in a competitive employment setting for employees with intellectual disabilities: A systemic review. *Journal of Occupational Rehabilitation*, 26: 56-69.

accessible formats (easy read), taking the time to know and understand the person and their situation and ensuring support for decision making.

Supporting decision making typically will involve families and others in support and advocacy roles in the person's life, who may also be the person's agent. It is critical that supporters or agents are fully informed so that individuals are able to exercise their right to equal recognition before the law (CRPD Article 12) and have the support required to make decisions.

Procedural requirements such as having to provide photographic identification can also pose problems for people with intellectual disability given that many people with intellectual disability do not have a passport or drivers licence.

Recommendation

10. Policies, processes and practices within the welfare system recognise the right of people with intellectual disability to have information in accessible formats and to have support to make decisions.

8. Alignment across government and working with communities

IHC strongly supports the welfare system being part of an integrated Government approach to ensuring everyone has a dignified life. The welfare system is inextricably linked to other systems across Government including in the tax, health, education, and Oranga Tamariki systems, as well as policy settings in areas such as housing, employment and business.

Meeting the stated aims of the welfare system, for people with intellectual disability and their families, will require government to work collaboratively with communities, NGOs and people with intellectual disabilities and their families in the design, planning, implementation and review of welfare policies and practices.

Barriers to getting a good alignment across Government include complex and disconnected rules and regulations, burdensome procedures and differing eligibility criteria that add more complexity and bureaucracy.

The practicalities of what counts as income and therefore affects welfare entitlement is a major issue that also needs clarification, especially as New Zealand moves towards individualised funding of disability support services. Similarly, issues around people and their families employing support staff, have yet to be adequately addressed.

Recommendation

11. The welfare system is linked to other government systems and policy settings so that people with intellectual disability and their families can expect an integrated and accessible response to their circumstances.

9. Transformation of the Disability Support System

“Financial hardship adds an extra burden to families already struggling to do their best for their disabled loved ones, limiting their choice and control over a long period of time.”
IHC 2017 survey respondent¹⁰

The disability support system is currently undergoing transformation, based on the Enabling Good Lives (EGL) vision and principles¹¹. The EGL vision is that in the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.

EGL is based on the principles of:

- self-determination
- beginning early
- person centred
- ordinary life outcomes
- mainstream first
- mana enhancing
- easy to use
- relationship building.¹²

We suggest that principles underpinning the welfare system should be consistent with, and support, the EGL principles.

Recommendation

12. The principles underpinning the welfare system are consistent with, and support, Enabling Good Lives (EGL) principles.

10. Children and youth with disabilities and their families

“...due to the severity of my child’s disability and the level of home care I need to provide we only have a single income and a small weekly child disability allowance. This barely gets us week to week and doesn’t allow for additional expenses. We are providing education at home due to the limited hours allowed from my child’s ECE centre.”
IHC 2017 survey respondent¹³

One of the overall aims of the welfare system should be to support parents to raise their children, so that collectively, as a society, we create the conditions needed for all children, including those with disability, to have great childhoods and adolescences.

Children with disability are over-represented in, and therefore disproportionately affected by, the welfare system. Assessing the impact of the welfare system on children should include a focus on children with disabilities and their families. Arguably, if the welfare system works to improve the wellbeing of children with disabilities and their families it will work for all children and families.

¹⁰ IHC 2017 How is New Zealand doing for people with intellectual disabilities? www.ihc.org.nz/survey

¹¹ <http://www.enablinggoodlives.co.nz/about-egl/>

¹² <http://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/>

¹³ IHC 2017 How is New Zealand doing for people with intellectual disabilities? www.ihc.org.nz/survey

10.1 Improving children’s wellbeing – reducing child poverty

An effective welfare system is critical to reducing child poverty as defined by the Children’s Commissioner’s Expert Advisory Group (EAG) on Child Poverty: “Children living in poverty are those who experience deprivation of the material resources and income that is required for them to develop and thrive, leaving such children unable to enjoy their rights, achieve their full potential and participate as equal members of society.”¹⁴

IHC supports the definition of a child as a person under the age of 18. However, children and young people experience a wide variety of life stages before the age of 18 as babies, young children, older children and adolescents. The welfare system needs to be flexible enough to respects the rights and meets the needs of children and youth with disability in age appropriate ways at different life stages.

Due to the very limited data available on the circumstances and experiences of children with disability it is impossible to accurately assess how many children with disability live lives impacted by poverty. However, based on the data that is available, children with disabilities are more likely to live in poverty, using the EAG definition, than their non-disabled peers¹⁵.

10.2 Children first, as part of family and whānau

Children with disabilities are children first, entitled to “enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.”^{16 17}

In 2016 the United Nations Committee on the Rights of the Child recommended that the New Zealand Government adopt a comprehensive, child rights and participatory approach to the fulfilment of the rights of children with disabilities; that more needed to be done to combat the marginalisation and discrimination of children with disabilities in their access to health, education and care and protection, particularly for Maori children with disability, children with disabilities living in poverty and children with multiple disabilities.¹⁸

These recommendations recognise that children with disabilities are not an homogenous group; their experiences vary, depending on their individual circumstances. A respondent in IHC’s 2017 survey on how New Zealand is doing for people with intellectual disabilities explained “*If you are from a wealthy family and/or a family with high cultural capital things may go well but that is a matter of happen-chance and many are left behind.*”

In order to promote equality and eliminate discrimination (as required under UNCROC¹⁹ and the UNCRPD²⁰) the rights of children with disability need to be protected and advanced by the welfare system.

As a minimum, the welfare system should be consistent with the general principles of children’s rights. It should:

¹⁴ Office of the Children’s Commissioner (2012) Solutions to Child Poverty in New Zealand: Evidence for Action.

¹⁵ See Wynd, D. *‘It shouldn’t be this hard’: children, poverty and disability*. Child Poverty Action Group. February 2015.

¹⁶ Article 23, United Nations Convention on the Rights of the Child. New Zealand ratified this Convention in 1993.

¹⁷ Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which New Zealand ratified in 2008, re-enforces the rights of children with disability and emphasises that children with disabilities are entitled to enjoy their rights on an equal basis with other children.

¹⁸ CRC/C/NZL/CO/5 Committee on the Rights of the Child *Concluding observations on the fifth periodic report of New Zealand*. Paragraph 30.

¹⁹ The United Nations Convention on the Rights of the Child

²⁰ The United Nations Convention on the Rights of Persons with Disabilities

- apply without discrimination to all children²¹
- ensure the best interests of the child is a primary consideration in all decision-making
- support, to the maximum extent possible, the survival and development of the child
- take into account the views of the child.

Recommendations

13. The WEAG support the United Nations Committee on the Rights of the Child recommendation that the New Zealand Government adopt a comprehensive, child rights and participatory approach to the fulfilment of the rights of children with disabilities and ensure that the welfare system responds to the numbers of disabled children living in poverty.²²
14. As a minimum, the welfare system should be consistent with the general principles of children's rights and;
 - apply without discrimination to all children²³
 - ensure the best interests of the child is a primary consideration in all decision-making
 - support, to the maximum extent possible, the survival and development of the child
 - take into account the views of the child.

10.3 Children's wellbeing depends on family and whānau wellbeing

Children's wellbeing cannot be considered in isolation from their family's wellbeing²⁴.

The welfare system should also give effect to another central tenet of children's rights; recognition that children exist within families and that children have the right to be guided and cared for by their parents and family and whānau, and parents are entitled to state support in their important child rearing role.²⁵

The child's right to an adequate standard of living should be understood as one which allows a family environment and atmosphere that enables a child to live and grow to their full potential.

The welfare system is one way in which Government can ensure children have an adequate standard of living. The welfare system should also reduce and mitigate the effects of financial and other stresses on families and the children within them.

Appropriate level of support

The welfare system needs to be flexible enough to provide a level of support commensurate with the reality of the lives of children with disability, based on:

²¹ It should be noted that New Zealand has a reservation to the Children's Convention that means it does not have to be applied to children unlawfully in New Zealand.

²² CRC/C/NZL/CO/5 Committee on the Rights of the Child *Concluding observations on the fifth periodic report of New Zealand*. Paragraph 30.

²³ It should be noted that New Zealand has a reservation to the Children's Convention that means it does not have to be applied to children unlawfully in New Zealand.

²⁴ The preamble to the Children's Convention recognises the family as the fundamental group of society and the natural environment for the growth and well-being of all its members, particularly children. The Convention regards growing up in a family environment, in an atmosphere of happiness, love and understanding, as essential to the full and harmonious development of the child's personality

²⁵ Children's Convention Articles 5, 18 and 27.

- research evidence
- the views, experiences and circumstances of individual children and families.

Despite a paucity of data, much is known about the issues facing children and youth with disabilities and their families.

IHC's *What's important for family wellbeing?*²⁶ report found that many families with children with intellectual disability find it hard to get the life others take for granted. The report identified four themes as important for family wellbeing – attitudes, belonging and inclusion, fair systems and being able to plan with confidence and good support and connections.

Similarly, the Good Start in Life project²⁷ is based on a number of known issues that are relevant to potential changes to the welfare system. These issues include:

- Parents, family and whānau being valued and having choice and control.
- More timely identification/recognition of need.
- More timely access to disability supports (capacity, eligibility criteria, geographical coverage).
- Increased access to disability supports – not targeted only to very high need.
- Easier access to disability supports – good information, less complexity, fewer hoops.
- Continuity of access over time and when people shift.
- Services and supports strengths-based and aligned with good practice.
- More consistent, coherent and better integrated supports and services.

The welfare system and the disability support system

Central to the wellbeing of intellectually disabled children, young people and their families and whānau is timely access to integrated, flexible and high quality universal and specialist supports and services. Yet this access can be fraught and variable, depending on the family's circumstances. As a result, families report feeling worn down and worried for their child's future.²⁸ The welfare system should enable access to universal services and other supports, not create additional barriers.

Sanctions

Benefit sanctions affecting families with children need to be abolished immediately.

We note with concern figures from the Child Poverty Action Group that in the June 2018 quarter alone 3371 sanctions were applied to beneficiaries with dependent children for such as failing to attend meetings or not naming the father on the welfare application.

Children with disability are more likely to be living in a sole parent household. IHC frequently hears of parents who are told their child can only attend school for limited hours, making it difficult for the parent to work. Families with children with disabilities often face additional costs, such as transport to appointments. We are therefore extremely concerned that children with disability are particularly vulnerable to benefit sanctions undermining their wellbeing.

²⁶ IHC *What's important for family wellbeing?* 2016. Available here: <https://ihc.org.nz/advocacy>

²⁷ Action 4B under the Disability Action Plan) is about developing policy options to improve the government supports for parents, family and whanau of disabled children aged 0-8 years. <https://www.odi.govt.nz/nz-disability-strategy/outcome-7-choice-and-control/#progress>

²⁸ This was a key theme to come through in IHC's 2017 survey on quality of life for people with intellectual disabilities. <https://www.ihc.org.nz/survey>

Child disability allowance

The numbers of children granted the Child Disability Allowance (CDA) almost halved between 2007/2008 and 2011/2012 (2012 is the latest MSD statistical report available)²⁹. This was despite the numbers of children with disabilities rising over that period. The decline in the number of CDA recipients raises serious questions about whether children with disabilities and their families and whānau are receiving their support entitlements and the processes they have to go through to do so.

Recommendations

15. The welfare system be flexible enough to provide a level of support commensurate with the reality of the lives of children with disability, based on research evidence as well as the views, experiences and circumstances of individual children and families.
16. The welfare system enable access to universal services and other supports, not create additional barriers.
17. Benefit sanctions affecting families with children need to be abolished immediately.
18. Take steps to ensure all children with disability and their families receive their support entitlements, including the child disability allowance.

11. Conclusion

“Some stories enhance life, others degrade it so we must be careful about the stories we tell and about the ways we define ourselves and other people”

Burton Blatt (1987)³⁰

IHC welcomes the opportunity to contribute to the work of the Welfare Expert Advisory Group.

We ask that your advice on the future of the welfare system take cognisance of issues for people with intellectual disability and ensure they are treated with and live in dignity – the unique contributions of people with intellectual disability are part of building a better future for all New Zealanders.

An effective welfare system is an essential component of an integrated government approach to supporting families with children with disabilities and enabling adults with intellectual disability to live a good life, as valued and active citizens in the community.

IHC believes the welfare system, along with other systems, should be underpinned by human rights to demonstrate and embed the values of compassion and respect within the context of universal supports, social justice and self-determination.

Trish Grant

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²⁹ CCS Disability Action The Rise and Fall of the Child Disability Allowance. <http://includingallpeople.org.nz/?p=900> posted 9.9.2014; See also Johnson A and Suri J, *Barriers to support: Uptake of the Child Disability Allowance in Otago Child Poverty Action Group* 2016.

³⁰ Burton Blatt (1987) cited in John O'Brien and Beth Mount (1991), Telling new stories: The search for capacity among people with severe handicaps. In L.H. Meyer, C.A. Peck and L. Brown (Eds.) *Critical Issues in the Lives of People with Severe Disabilities*. P.89.

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