

Counting what matters - Valuing and making visible the lives of children with disabilities

***Supplementary information for the United
Nations Committee on the Rights of the Child***

Action for Children and Youth Aotearoa

August 2016



Counting what matters Valuing and making visible the lives of children with disabilities

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Outline

- 1 This paper contains supplementary information about disabled children in Aotearoa New Zealand (Aotearoa NZ). It identifies three key themes regarding the Government's treatment and consideration of disabled children. The remainder of the paper sets out the situation of disabled children as it relates to the following specific cluster groups under the revised reporting guidelines CRC/C/58/rev.3:
 - Violence against children
 - Family environment and alternative care
 - Disability, basic health and welfare
 - Education, leisure and cultural activities
 - Special protection measures.
- 2 Case studies are also included to further illustrate and strengthen the points made in this paper (see the Appendix).

Prevalence and information about disabled children and their families

- 3 The lack of robust data about disabled children and their families has been a prevalent and ongoing issue in Aotearoa NZ for many years. The *New Zealand Disability Survey* is currently one of the only data sources incorporating disaggregated information about disabled children. The *2013 New Zealand Disability Survey* estimated that 95,000 or 11% of children under 15-years are living with a disability with:¹
 - the most common impairment (52 %) relating to learning difficulties
 - the most common cause of impairment (49 %) being a condition that existed at birth
 - learning, psychological/psychiatric and speaking difficulties being the three most common main impairments
 - almost half (48 %) of children living with the effects of multiple impairments.
- 4 The *2013 New Zealand Disability Survey* and Statistics New Zealand also identified a number of disadvantages that children with disabilities and their families are experiencing. These included:²
 - 34 % of disabled children living in families that earn under \$50,000 a year, compared to only 24 % of non-disabled children
 - 17.7 % of disabled children living in households that earn under \$30,000 a year, compared to 11.5 % of non-disabled children
 - 5 % of disabled children living in households that earn under \$15,001 a year, compared to 3.8 % of non-disabled children
 - Māori children being more likely to experience psychological/psychiatric impairments, difficulty with learning and speaking and intellectual disability than non-Māori children
 - estimates that disabled children were less likely, in the previous four weeks, than non-disabled children to have had music, art, or other similar lessons; played a team



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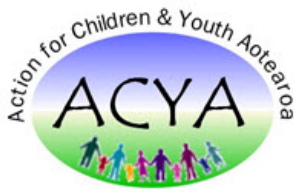
sport; done other physical activity such as swimming or gymnastics; visited friends; or been away on holiday in the last 12 months.³

Overarching themes of this paper

- 5 Despite New Zealand's ratification of the United Nations Convention on the Rights of the Child (CRC) and the United Nations Convention on the Rights of Persons with Disability (CRPD) there is little evidence that these frameworks have been used in the development of child policy and/or government agency strategic documents. Disabled children remain marginalised and children with intellectual disability or developmental delay are all but invisible in strategic documents and child policy. Our analysis of the situation of disabled children in Aotearoa NZ has identified the following themes:
 - children affected by disability are largely either invisible or treated differently, under government policies, including in areas such as health, education and care and protection
 - previous reports to the United Nations (UN), and concluding observations issued by the UN, have repeatedly highlighted that government decisions, policies and practices in relation to disabled children have been rudimentary
 - the lack of a coherent, rights-based approach to government services for disabled children and their families has significant detrimental effects on their wellbeing and life outcomes.

Disabled children – invisible and separate

- 6 Alternative reports submitted by ACYA⁴ and the UN Committee on the Rights of the Child concluding observations have consistently highlighted that successive governments have not addressed a number of significant issues relating to the rights afforded children under the CRC. Policies affecting children tend to be piecemeal and ad hoc with little recognition of the interdependent and interrelated nature of children's rights. Sadly, this experience is even more heightened for children affected by disability in Aotearoa NZ.
- 7 Yet children with disabilities do not stand in isolation of their peers. They are connected to schools, communities and other supports. Their experiences of these environments dictate their future outcomes.
- 8 A nation's approach to disability is driven from the leadership and stewardship of its government, which can either positively impact the building of capacity, competence and confidence or give rise to marginalisation, helplessness and fear. These are reflected in the expectations government has and the messages it gives about how people can and should be able to live their lives; how welcoming and inclusive communities are; how ethical, policy and funding decisions are made; the quality of services and supports provided; and what safeguards are in place.⁵
- 9 Despite the ratification of the CRC, a structural mismatch remains between processes required to ensure implementation of the CRC, and the way government policy and practice is developed for children in Aotearoa NZ generally. Yet even with the ratification of the CRPD, under which the Government has put in place monitoring



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mechanisms, the voice of the disabled child is still not being heard or valued. Therefore, despite two international treaty-level conventions that have required successive governments to place a children's rights lens over all policies and legislation impacting children, disabled children continue to experience poorer life outcomes than their non-disabled peers.

Decisions, policies and practices affecting disabled children are rudimentary

- 10 It is deeply concerning that despite having UN instruments that explicitly identify and recognise the needs of children with disability, monitoring and reporting under these UN instruments has repeatedly highlighted that government decisions, policies and practices in relation to disabled children have been rudimentary. There is a clear disconnect between the commitment that successive governments in Aotearoa NZ have made to their citizens in signing up to and ratifying the UN's core human rights instruments and their subsequent actions and decisions. In fact, the UN and the Human Rights Council have found significant gaps in government decision-making processes, and implementation of policies and services as they apply (or not) to the needs of disabled children and their families.
- 11 Successive reporting cycles and periodic reports have failed to include children with disabilities in the community of all children. In addition scant attention has been paid to the specific needs of disabled children and their families, including the accommodations, additional supports and specialist services that may be needed. There is a failure to see the child first and too often disabled children are defined by their disability label and seen as 'other' or a 'burden.'
- 12 Compounding the lack of visibility of children with disabilities is their absorption into the general descriptor of disabled people. The Government's work under its CRPD goals is a clear example of this. The CRPD has given Aotearoa NZ a new lens to consider the lives and wellbeing of disabled children and their families. This includes the way we monitor our laws, policies and practices as a civil society. However, the focus has remained almost entirely on adults. For example, government mechanisms, including a Ministerial Committee, a National Plan of Action and a monitoring body (that includes all Disabled Persons Organisations (DPOs)) primarily represent and advocate for the needs of adults.
- 13 Aotearoa NZ does not have a national body, which has the specific responsibility of representing children and young people with disabilities. This is despite Article 4 of the CRPD which states that, "... in the development and implementation of legislation and policies to implement the present Convention and other decision-making processes concerning issues relating to persons with disabilities, governments shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations."
- 14 Without a children's DPO any government decisions on policies affecting all children, will not include the direct experience, data and studies about/from children and young people with disabilities. This in turn means there will continue to be a disconnect between the reality of children's lived experiences and the laws, policies and programmes which purport to improve their situations. Until the voices and lived



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experiences of children with disabilities are placed at the centre of policy making, the policy gains we achieve under the framework of the CRC and CRPD will be limited.

Current approaches have significant detrimental effects on wellbeing and life outcomes

- 15 The lack of visibility and inclusion in UN reporting processes is replicated in the Government's domestic policy and practices for all children and young people in Aotearoa NZ. The Government also has specific strategies and policies that directly concern and are primarily focused on people with disabilities. The core agencies of the Ministries of Education (MOE), Health (MOH), and Social Development (MSD) have direct responsibilities for these strategies and policies.
- 16 An analysis of these agencies' Statements of Intent, and their Four-Year strategic plans yields limited results on specific strategies for children with disabilities. We would have expected to see references to the CRC, the CRPD and to a lesser extent the Universal Periodic Review – particularly for MSD, which has a monitoring and coordination role for the CRC and a similar role for the CRPD via the Office of Disabilities Issues (ODI). There should have been explicit statements, analysis, outcomes and targets for disabled children and their families. However, disappointingly, this is not the case.
- 17 Whatever the reasons for these omissions, the inconsistencies, absences and lack of recognition, let alone inclusion is symptomatic of the Government and the wider public sector's systematic and systemic failure to:
 - meet its international human rights obligations
 - recognise that children with disability are valued members of our community
 - actively and deliberately consider and incorporate the needs of children with disability in the development of their strategic foci and activities as a matter of course.
- 18 Families must navigate different agencies and funding streams, which can add to stress. Struggles to find information combined with a lack of informal or formal supports make things harder. Families become "tired and worn down"⁶ from continually having to fight battles to get help and to get the right support at the right time. There is a compounding of difficulties experienced when families are isolated and/or living on a benefit or low income.
- 19 Not being valued, not being able to get the right support at the right time, facing discriminatory practices from schools, and not having the right support to transition into adult life results in poor life outcomes.
- 20 Current policies and practices result in inequitable outcomes and difficulties in navigating systems that are not child-centred and/or driven by family preferences and culture. Families with children with disability typically have to navigate a complex maze, endure endless assessments and coordinate multiple services as well as meet their child's additional care needs. Lack of timely and flexible responses increase the stressors faced by families. This situation is not new and has existed for far too long. Some examples of the experiences of disabled children and their families are included as case studies in the Appendix to this paper.



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The situation for disabled children as it relates to cluster groups

Violence against children (Articles 19 and 39, 24(3), 37(a), 28(2), and 34)

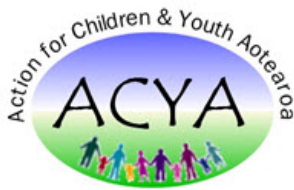
- 21 Disabled children are just as vulnerable to abuse and poor life outcomes (indeed more so) as the general child population but their circumstances are often only viewed through a disability lens. Disabled children are three times more likely than non-disabled children to be abused or neglected and these rates are even higher for children with communication impairments, behaviour difficulties, intellectual disability and sensory disabilities.

Family environment and alternative care (Articles 5, 9-18, 20-21, 25 and 27(4))

- 22 The Government has recently completed a comprehensive review of Child, Youth and Family (CYF) and is about to embark on a major overhaul of a child protection system that has been described as broken. There was scant consideration of children with disabilities in the review and papers released publicly. Thus far there is very little indication on how children with disabilities are to be considered within the new structures.
- 23 Currently, there is clear evidence of diagnostic overshadowing in consideration of a disabled child's requirements for care and protection. Often, care and protection workers only see the disability and attribute any family difficulties to the disability. This results in differential treatment of children with and without disabilities despite being in a similar situation. A very recent case highlighted this disparity when a child with a disability who had been left in the family home was killed, while the non-disabled siblings had been removed by the State.

Disability, basic health and welfare (Articles 6, 18, 23, 24, 26 and 27)

- 24 Children with profound and multiple impairments (high and complex needs) are particularly vulnerable to health problems. Some children with multiple impairments or high and complex health needs find it hard to obtain the specialist care needed. In addition those who are able to access specialist paediatric services can find it challenging to continue to access specialist expertise when they move from childhood to adult services. Accessing child psychiatric services can also be difficult, particularly for children with intellectual disability, where problems are often attributed to their intellectual impairment and seen as a disability support issue rather than as a health issue.
- 25 The MOH administers disability support services funding through Needs Assessment and Services Coordination Agencies (NASCs). Options for health services and support vary regionally, creating a disparity in what can be accessed. Many families report that funding does not filter down to the people who need it most. Often those parents *"who shout the loudest are the ones that are heard, [while] other people who may not have the energy, time or resources to shout fall through the cracks."*⁷
- 26 There are a number of initiatives underway trialling more individualised, flexible and integrated approaches. However, the disjointed nature of these initiatives lacks a



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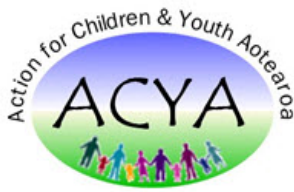
coherent vision and concern remains around whether there is sufficient Government commitment to making funding available to roll out successful pilots nationally and in a consistent manner.

Disability Action Plan

- 27 This paper contends that actions related to implementing and monitoring the CRPD, the New Zealand Disability Strategy and the Disability Action Plan are predominantly adult-focused. An example of this is the work currently being undertaken in the *Disability Action Plan 2014-2018* which presents priorities set by a Ministerial Committee on Disability Issues for action that advance implementation of the CRPD and the New Zealand Disability Strategy.
- 28 The Disability Action Plan focuses on actions that require cross-agency collaboration to achieve the desired outcomes. It also requires that government agencies fulfil their obligations under the CRPD, and work collaboratively with DPOs and allied organisations.
- 29 One of the few child-related actions in the Disability Action Plan is a cross-agency action called “A Good Start in Life” which tasks the MOE, MOH and MSD to develop policy options to improve government supports for parents, family/whānau with disabled children aged 0-8 years. The project includes a reference group comprising of DPO representatives, service provision representatives and parent groups. This is the second attempt at this goal; the first attempt having failed after government departments were unable to reach agreement on cost, funding and actions.
- 30 While we welcome the second attempt at getting this cross-government initiative off the ground, early indications show that a child’s rights lens, as required under both the CRC and CRPD, is not being applied. Quite apart from the fact that there is no children’s DPO at the table, the voices of children have thus far not been canvassed. The title of the group in itself (“supports for parents, family and whānau with disabled children aged 0-8 years”) shows the focus of the work remains on outcomes for families and parents, rather than outcomes for children and the full realisation of their rights.

Education, leisure and cultural activities (Articles 28-31)

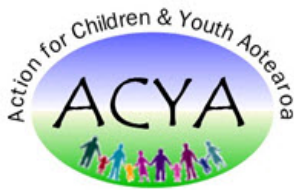
- 31 By its own admission, the Government’s education strategies are not reaching all disabled children. It is not difficult to make links between this failure and the growing numbers of children with disabilities in the youth justice sector. The MOE is aware that families do not receive information about the full range of services their disabled children are entitled to. In addition access to coordinated services and resources, particularly at the local level, are less than optimal, often disjointed or fail to focus on the holistic needs of disabled children.⁸
- 32 In 2015 the Education for All Network also highlighted concerns about special education in Aotearoa NZ in a submission to the UN Committee on the Rights of Persons with Disabilities.⁹ These concerns included:
 - schools struggling to respond to the rights, needs and interests of disabled children¹⁰



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- the Government's continued confusion over the definition of inclusive education and a lack of human rights focus in education for disabled students¹¹
 - MOE guidelines to schools and education policy documents currently not making reference to the CRPD or disabled students rights to reasonable accommodation¹²
 - identifying a gap between the right to education in the Education Act 1989 and the ability and means to enforce it, particularly for disabled students.¹³
- 33 It is not surprising that special education policy and strategies contain the most explicit references to and consideration of the needs of disabled children. After all, children spend a significant part of their formative years in school and other educational institutions. However, it is equally unsurprising that most of Aotearoa NZ's education policy fails to consider or meet the needs of children with disability, especially intellectual disability or developmental delay.
- 34 In turn, the failure to implement a fully supported inclusive education system means that disabled children, especially those with intellectual disability or developmental delay, do not enjoy equal participation and success in their schools, communities and families. Nor do they have the same level of independence and hope for the future that their non-disabled peers enjoy.



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Special protection measures (Articles 22, 30, 32-36, 37(b-d), 38-40)

- 35 Research evidence from the United Kingdom (UK)¹⁴ reported a significant over-representation of neurodisability (which encompasses intellectual disability, specific learning difficulties, autism spectrum disorder, ADHD, epilepsy, foetal alcohol syndrome and communication disorder) amongst young persons in custody. Discussion with Aotearoa NZ organisations and providers within the youth justice sector suggest that the rates are likely to be similar in our country. As an example, the UK report states that while children and young persons with learning disabilities make up 2-4 % of the general population, the prevalence rates amongst young people in custody is 23-32 %. Those with traumatic brain injury have a prevalence rate in custody of 65-72 %.
- 36 In 2014, research undertaken on behalf of the Donald Beasley Institute¹⁵ of Aotearoa NZ concluded there was a need to develop strategies “for ensuring lawyers and judges had the skills to communicate effectively with people with intellectual disability ...” Furthermore, these strategies, and the importance of understanding the context of people with intellectual disabilities lives, was critical to this group achieving equal recognition before the law and access to justice. While this research was with adults with intellectual disability many of the participants had had contact with children’s care and protection and youth justice services. A high percentage had also been victims of abuse but this had gone unrecognised or was not believed. Clearly our systems are failing children and young people with disabilities. This is particularly so for 17 year olds as they are dealt with in the adult justice system, not the youth justice system which is more able to take a restorative approach to offending.
- 37 The Government’s responses, through work led by the ODI has been to:
- commit to developing a National Data Standard for Disability within the justice sector to help understand disabled peoples’ journeys through the justice system¹⁶
 - ensure the MOH, Ministry of Justice and the Department of Corrections are working to ensure the criminal justice system is responsive in supporting prisoners with disability-related needs¹⁷
 - ensure government agencies understand the journey through the justice system for people with disabilities.¹⁸
- 38 Despite these specific action points we are not seeing the operationalisation of these points within agencies on the ground. As just one example, the New Zealand Police do not include or reference the Government’s Disability Action Plan work items in either their Statement of Intent or their Four-Year Plan.¹⁹

Appendix – Case Studies

Ben

- 39 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.
- 40 When Ben was two-years old he started going to an early childhood education centre (ECE) three mornings a week. Staff at the centre provided contact details for parent and community groups. Marion and Paul 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 to help other parents.
- 41 Ben's ECE teachers suggested that he be referred to the District Health Board Child Development Team (CDT). A practitioner from the CDT worked with Ben, Marion and the ECE staff to make adaptations to help Ben learn and participate with the other children at the ECE. 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.
- 42 Ben's experiences at primary 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 enrol Ben.
- 43 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 submitting an application to the Ministry of Education for Ongoing Resourcing Scheme funding, which was turned down. Scant reasons were given for declining the application aside from Ben not meeting the eligibility criteria.
- 44 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 "behavioural" 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 to Marion that they may have to cut Ben's hours at school even further than his three days of early finishes rather than Ben 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.

Becky's family

- 45 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.
- 46 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 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."

James

- 47 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 (CYF) became involved and despite the parents' statements that they would harm him CYF refused to take any legal protective action on the grounds that there were no care and protection issues. The CYF social worker attributed the problems to James's disability. James was placed in an emergency mental health forensic unit where it was considered that he had been inappropriately placed. The unit agreed to develop a specialised one-to-one respite service in the local community. Specialist and respite staff agreed James could, over time, be placed back at his local school and live in a foster home after a few months in the one-to one-respite service.
- 48 A proposal from the community agencies was submitted to CYF. The community agencies advised CYF that it was unlikely that the respite care service would agree to enter into an out-of-home placement agreement in light of the parents' unwillingness to engage with them. 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. If it had been classified as a care and protection issue, CYF would have had grounds to become involved. While waiting for approval from CYF to provide the one-to-one service, the Ministry of Health agreed to fund an out of home placement 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 Ministry of Health ever communicated to one another about this or whether the Ministry of Health was aware of the proposal for a placement in the local community.
- 49 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, to a more expensive option than that proposed by experts on the ground working with James.

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Brian

- 50 Brian is 15-years old 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. Ministry of Health- Disability Support Services funded behavioural support services that worked successfully with Brian and his family to develop strategies to manage his behaviours.
- 51 Special Education staff had worked with Brian and the school staff to manage his behaviours at school. This had not been successful and the 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.
- 52 Brian's parents suggested the school utilise the expertise of the Behaviour Support Service they are using successfully at home. The school and 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.
- 53 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.

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- ² Ibid.
- ³ Statistics New Zealand. (2013). Social and economic outcomes for disabled people. Findings from the 2013 Disability Survey. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/social-economic-outcomes-13/social-contact-participation-community.aspx
- ⁴ Refer to www.acya.org.nz for these documents.
- ⁵ IHC. (2015). *Valued, good and ordinary lives*. Retrieved from <http://www.ihc.org.nz/valuedlives>
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- ¹⁰ Ibid, p.2.
- ¹¹ Above at note 8, p.3.
- ¹² Above at note 8, p.4.
- ¹³ Above at note 8, p.5.
- ¹⁴ Hughes, N., Williams, H., Chitsabeau, P., Davies, R. & Mounce, L. (2012). *Nobody made the connection: The prevalence of neurodisability in young people who offend*. London: Office of the Children's Commissioner.
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- ¹⁶ Ministry of Social Development. (2015). *Towards an inclusive and enabling New Zealand: The annual report from the Minister for Disability Issues to the House of Representatives on implementation of the New Zealand Disability Strategy*. Wellington: Office for Disability Issues. Retrieved from www.odi.govt.nz, p.25.
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