INTRODUCTION

Endeavour Foundation is the largest disability services provider in Australia, providing care and support to more than 3,350 people living with a disability. Endeavour’s work includes children and young people under Child Protection orders, as well as children who have come to the attention of Child Protection Authorities where attempts are being made to preserve the family.

We welcome this opportunity to contribute to the Queensland Commission of Inquiry into Child Protection and for the voices of children and young people with a disability to be heard. With previous inquiries focusing primarily on types of care (i.e. institutional care or foster care) the complexity of caring for children with a disability has not been given any focus.

Often children with a disability are invisible in their communities as a result of the marginalisation and social isolation experienced by their families. A gradual loss of community and social cohesion has seen the contracting of natural networks within communities who would have in the past provided support. Where once a neighbour would have lent a hand and found ways to help out a family in distress, today that same neighbour will report concerns to authorities.

Child Protection is the responsibility of society as a whole, not just one Government Department. There is a responsibility beholden on all Government Departments to legislate and develop policy that ensures children and their rights are protected. Government is also responsible for providing the best possible system or framework to support the endeavours of those responsible for delivering Child Protection outcomes. It is erroneous to hold one Department accountable for all things Child Protection.

Endeavour Foundation argues that an integrated child protection system that includes universal supports, early intervention and appropriate secondary supports for families caring for a child with a disability will provide better outcomes for children and their families (see Figure 1 below).

Figure 1: Child Protection Continuum
BACKGROUND

Children and young people with a disability come into the Statutory Child Protection System through one of two pathways: either through a child protection concern or through parental relinquishment of guardianship to the State. Endeavour Foundation works with children and families that reflect both of these pathways. In the case of relinquishment, parents or carers have not been provided with sufficient supports to enable them to care for their child at home. In this situation, parents feel that they have no other option but to relinquish their child to the Child Protection System.

Children and young people with a disability are over-represented within the Child Protection System. In Queensland an estimated 22 percent of children and young people in care are living with a disability, which is consistent with estimates across all Australian jurisdictions. Within this population, it is difficult to establish the prevalence of relinquishment as no systematic data is collected either in Queensland or nationally. A 2012 report by the Victorian Equal Opportunity and Human Rights Commission was able to estimate that 50 children were in care due to relinquishment at the time of the report. However, service providers have also reported that there is approximately another 800 children in care in Victoria who have been relinquished.

Endeavour works with families who have felt they have no other option but to relinquish their child. Endeavour has witnessed the distress and disintegration of families, where parents bear the shame of not being able to fully care for their child, and the child experiences compounding trauma due to disruption of attachment to their main care givers. Endeavour is also aware that parents are sometimes informed by frontline staff (either Departmental or other professionals) that the only way their child will receive the supports they need is through relinquishment, as more funding is available due to the statutory nature of care. In the experience of Endeavour, the majority of children relinquished are boys (aged 12 years and over) with autism, intellectual disability and other diagnoses.

Endeavour also provides care to children and young people who have come into the Child Protection System due to protection concerns. Whilst these children require a child protection response, Endeavour has found that this rarely takes into account the additional requirements necessary to meet the needs of a child with a disability. Such children are often assessed and categorised within the Complex to Extreme behaviour spectrum where they attract higher levels of funding, however corresponding supports are not allocated that ensure placement stability and the best outcomes for these children. We have often heard staff from the Department of Communities, Disability Services comment that they are the poor cousins of Child Safety due to funding disparity.

Where children are placed in foster care, rarely are supports provided to the foster carer to understand and adequately meet the needs of the child with a disability. This results in a higher degree of placement breakdown for children with a disability. Many of these young people are placed in 24/7 Youth Worker Support models within the High Cost Placement model.

Throughout this submission we focus exclusively on the specific situation of children with a disability and their families. We argue that the current Child Protection System is failing to adequately protect the rights and best interests of children with a disability who are over-represented within the system. We argue that families require and should receive sufficient supports to care for their children and young people.

children at home, enabling them to avoid relinquishment, maintain their family unit and achieve the best possible outcomes for their child. Where it is in the best interests of the child to come under the care of the Child Protection System, we argue that a specialised response is vital for a highly vulnerable population that is currently not well served by the system.

SECTION 1: PARENTING A CHILD WITH A DISABILITY

1.1 Receiving Adequate Support

Raising a child with a disability can be a challenging experience for families. A wealth of research has demonstrated the considerable psychological, social, and financial impact on family quality of life. It is common for parents to report higher than normal levels of stress, depression and anxiety especially when their child experiences multiple or severe impairments or high behavioural support needs. Spousal relationships and relationships with other children within the family are sometimes negatively impacted by this strain. Families frequently report a sense of isolation from the community due to restricted social activities and inadequate informal supports. Families are also highly likely to experience financial strain if care responsibilities reduce parents’ ability to engage in paid work.4

Under such circumstances, the provision of adequate support is essential to mitigate these effects and preserve families. The United Nations Committee on the Rights of the Child has issued a General Comment on the Rights of Children with Disabilities which states that:

*Children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects.*5

Adequate support is described as that which protects a child’s rights and would allow him or her to continue to live with their parents whenever this is in the child’s best interests. Support services need to address any specific needs of the child, and enable parents to work, to relieve stress, and maintain healthy family environments. Access to respite care, including in-home assistance and day-care facilities, can prevent families reaching crisis point. Recent Australian research has confirmed that access to respite care is a key strategy for the prevention of relinquishment.6

Research has also established that unmet need for support is one of the strongest predictive factors for relinquishment of children with a disability.7 In the current context, it is widely accepted within Australia that there is significant unmet need for disability services nationally. As part of the new National Disability Strategy, the Productivity Commission investigated disability support in response to “concerns about systemic and long-standing inadequacies in disability care and support across Australia, and the consequent impact on people with disabilities and their carers”.8 The Productivity Commission found that:

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The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.\textsuperscript{9}

With regard to relinquishment, the Productivity Commission received considerable testimony from parents struggling with care. Relinquishment was a difficult decision that carers made only after years of attempting to cope with insufficient formal supports. The cost to the system of delivering support to children for whom care has been relinquished is significant, compared to the cost of delivering support such as early intervention and respite programmes that prevent crisis.\textsuperscript{10}

The Productivity Commission has recommended significant changes to the way that disability services are funded and delivered in Australia with the introduction of a social insurance model, the National Disability Insurance Scheme (NDIS). The NDIS would provide individually tailored, taxpayer-funded support for people with significant disabilities assessed as needing support. An integrated system that encompasses a continuum of response and can provide appropriate and timely supports to families will provide a solid foundation to reduce the incidence of relinquishment of care. Endeavour Foundation supports the introduction of the NDIS and regards it as a key strategy to improve the support of children and preservation of families.

**Recommendation 1**
Endeavour Foundation urges the Queensland Government to support the implementation of a national NDIS.

**1.2 Universal Services**

Universal services play a critical role from the outset for a family with a child with a disability. Health, Housing, Education, Child Care and Community Services may all be key points of contact for a family in this situation. Many families have contact across all these areas; however, each system works in isolation from the others without common information sharing which would provide a better depiction of the needs of families.

At the diagnosis stage, families need to have available to them a range of supports and information about how to access them. A case manager should also be appointed to prepare a life time plan for the child that follows the child through various stages of childhood and transitions, identifying additional supports that may be required at each point. Case planning could be outsourced to specialist disability service organisations who can maintain a long-term relationship with the family as a primary support, providing information and advice when required and facilitating connection to services. This strategy would prevent children and families from slipping through the gaps in the service system.

**Recommendation 2**
Establish a Case Management program where a child diagnosed with a disability is appointed a Case Manager responsible for life time planning and identifying family support needs to support family preservation.

\textsuperscript{9} Productivity Commission, page 2.
\textsuperscript{10} Productivity Commission, page 143-144.
1.3 Early Intervention

Children with intellectual disabilities are at increased risk of maltreatment in the form of abuse or neglect.\textsuperscript{11} In order to meet the needs of children with a disability and ensure healthy family environments, an early intervention support framework needs to be adopted. Such a framework needs to focus on providing support that is tailored to the unique context of each family, addressing the needs of the child with a disability as well as seeking to enhance quality of life for the entire family unit. Family-centred practices are internationally regarded as important for the delivery of services to children with a disability. Family-centred professional support that is comprehensive, well-coordinated, and delivered in a supportive and respectful manner, has been found to be one of the strongest predictors of positive family quality of life when the family includes a child with a disability.\textsuperscript{12}

The families that Endeavour meets who have relinquished their children have mostly done so because they have not had the supports they need to maintain a safe and healthy environment which meets the needs of the child with a disability, as well as any siblings. By providing In Home Support and parent education to these families the long term cost savings will be significant. High Cost Packages can amount to up to $800,000 per annum for a young person with the most extreme and complex behavioural support needs. This model can require a 2:1 staffing ratio and a range of positive behaviour strategies to support staff to maintain their own safety and that of the young person. However, for the same cost over a childhood the family could have been provided In Home Support and respite that would have seen the family unit preserved, developing resilience and a broad range of community supports.

We commend the funding of Baby Bridges early intervention program for children under 5 years of age and argue that similar programs need to be established for those who are over 5 years of age.

**Recommendation 3**

Develop an early intervention strategy and programs that target families with children with a disability (across all age groups) to ensure the necessary supports are in place to preserve children living with their families.

1.4 Secondary Services

For many families the stress of caring for a child with a disability becomes too great, and parents or carers feel they have no other option other than to relinquish their child or young person to the Child Protection System with the belief that this is the only way they will receive the supports they need. There are many cases where relinquishment could be prevented if families were provided with a range of support options including In Home Support, Planned and Emergency Respite, Positive Behaviour Support Planning, Parent Education and Training and strategies for working with the child or young person. Research has established that increased requests for short-term respite breaks is a warning sign for relinquishment, and that extra supports directed to families in a timely manner can enhance carers’ ability to cope both in the short- and long-term.\textsuperscript{13}


\textsuperscript{13} Nankervis, Rosewarne & Vassos, 2011b.
Recommendation 4
Develop a secondary response system that can identify families under stress and provide additional supports to prevent relinquishment.

1.5 Indigenous Children with a Disability

No specific data relating to Aboriginal and Torres Strait Islander children with disability in out of home care in Queensland is available; however, it is safe to assume that they are over-represented. National census data indicates that ATSI peoples have 1.4 times higher disability rates, are more than three times as likely to have an intellectual disability, and more than twice as likely to have a long-term condition or disability that means they require support meeting self-care, communication or mobility needs.\(^\text{14}\)

Within the Child Protection System in Victoria, Indigenous children are 11 times more likely to be in out of home care than non-Indigenous children. In June 2011, 14 percent of children with a disability in out of home care in Victoria were from an Indigenous background.\(^\text{15}\)

Aboriginal and Torres Strait Islander children with disability experience the double disadvantage of indigeneity and disability. Despite higher rates of disability, Aboriginal and Torres Strait Islander people are under-represented in the uptake of primary and early intervention disability services due to service gaps and barriers. Aboriginal and Torres Strait Islander families may be less likely to seek help when struggling to care for children with a disability because of concerns about discrimination and agency assumptions about parenting skills. Histories of dispossession and cultural memories of the forced removal of children may also act as a barrier to seeking support. Relinquishment has specific cultural meanings for Indigenous people, and when it does occur, Aboriginal and Torres Strait Islander children experience additional traumas relating to a loss of connection to their community and culture and disruption to their cultural identity.\(^\text{16}\)

Aboriginal and Torres Strait Islander families require specific service responses that are culturally sensitive and focus on a community development approach. This approach requires training and development to build community capacity to respond locally, as opposed to external services coming and going from a community.

Recommendation 5
Develop a culturally appropriate early intervention service model that is grounded in cultural identity, community development and capacity building to support communities to respond locally.


SECTION 2: WITHIN THE STATUTORY CHILD PROTECTION SYSTEM

2.1 Appropriate Responses to Children with a Disability in Care

Endeavour Foundation argues that the Child Protection System is not well placed to care for children and young people with a disability. Caring for someone with a disability requires a specific skill set. We have found that often Child Protection workers, Education staff and others only see the young person’s disability and do not take into account the compounded traumas that are known to occur for all children in care as a result of disruption to family-based identity and sense of belonging, attachment disorders, isolation from known environments, the stigma of living in care, and placement breakdown. These traumas commonly result in behavioural escalations for children in care; however, there is limited acknowledgement that children with a disability also experience these traumas and may indeed be even more vulnerable to such psychological stressors. Children with a disability who exhibit challenging behaviours while in care are frequently not “merely” disabled, but in fact are attempting to communicate distress.

Where a child does require care and protection, Endeavour recommends an alternative pathway for children with a disability that responds to a child or young person’s specific needs. Where forensic investigation is required, these investigations are best managed and performed by Child Safety, however when a child is identified with a disability, there needs to be a referral pathway that ensures the child is provided with adequate supports through specialist disability service organisations.

Recommendation 6
Establish a referral pathway for children with a disability entering the Child Protection System that ensures the child is provided with adequate supports through specialist disability service organisations.

2.2 Data Collection

As stated earlier, children and young people with a disability are over-represented within the Child Protection System. In Queensland an estimated 22 percent of children and young people in care are living with a disability, which is consistent with estimates across all Australian jurisdictions. However, this is an estimate only as no accurate data is collected, or made publicly available. Without accurate data collection, the magnitude of this issue cannot be fully known. Endeavour is aware that there are approximately 200 boys aged 12 years and over on the Asperger’s or Autism spectrum within the care system. Many of these young people live with multiple diagnoses and are difficult to place within home based care environments. With adequate data collection, issues for children with a disability within the care system could be better mapped and responses developed.

Data collection is also inadequate with regard to children with a disability known to the Child Protection System where families are struggling and exhibiting indicators for relinquishment. With better data collection and communication of this data, families could be identified before breaking point and interventions established to preserve families or plan for appropriate care pathways.

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18 Victorian Child and Adolescent Monitoring System (VCAMS)
Recommendation 7
Reliable and accurate data systems need to be developed that provide information state-wide and regionally on the disability of children and young people known to the Child Protection System, either as a risk of entering care or already in care. This data needs to be available to service providers attempting to respond to this vulnerable population.

2.2 Types of Care Provided

Within the Statutory System the placement of choice is Foster Care. Research evidence supports the view that a home and family environment that is supportive and nurturing is associated with the best quality of life for a child or young person to heal traumatic experiences.19

Due to the complexity of care needs for many children with a disability, Endeavour supports the employment of Specialist Foster Carers who are provided a salary, a higher level of training to meet the needs of the child or young person, and a requirement to care for only one child or young person at any one time. Queensland’s current Intensive Foster Care model falls short on providing adequate recognition and remuneration to foster carers commensurate with the complexity and challenges faced when caring for a child with a disability.20 Intensive Foster Care provides an appropriate response for children and young people living with mild to moderate disability. The Specialist Response Foster Care Model is a better match for children within the complex to extreme classification with a disability.

Recommendation 8
Expand the Specialist Response Foster Care Model in order to meet the needs of children and young people with a disability who are assessed on the complex to extreme spectrum.

Recommendation 9
Intensive Foster Care be provided to children and young people living with a disability who are assessed on the mild to moderate spectrum.

Many young people with a disability are placed in residential care along with other young people, co-tenanted in a privately rented (or Department of Housing) house in the community, or within a 1:1 youth worker model where they are the sole occupant. There are some young people who are unable to be co-tenanted due to serious risks to themselves and other young people, while others are placed in tenancy arrangements which expose them to serious risk of harm from other young people. Research from the US has found that young people with an intellectual disability are more than twice as likely to live in institutional settings as young people without a disability.21

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20 Dept of Communities, Strategy, Policy, Programs and Performance (2011). *Specialist Foster Care review: Enhanced foster care literature review and Australian programs description*. Quality Care; Child Protection Development; Child Safety, Youth and Families Community Participation.
Endeavour considers that family based care is the best placement option for children and young people. However, where this is not available, young people aged over 12 years should be co-tenanted in an environment and service model that replicates family based care and upholds the UN Convention of the Rights of the Child and UN Convention on the Rights of a Person with a Disability. It is imperative that existing residential care models within Queensland be reviewed and developed to better meet the needs of young people with a disability, including staffing qualifications and expertise required to best support this group of young people.

**Recommendation 10**
Review and develop a residential care model that supports the needs of young people with a disability together with the necessary expertise and qualifications required from staff.

### 2.3 Placement Instability

Due to the complex nature of caring for a child with a disability there is a greater risk of placement instability, and children and young people with an intellectual disability have been found to experience a greater number of placements than other children and young people in care. Placement stability has been shown to be an indicator for successful transition to adulthood for all children and young people in care.

Children with a disability as teenagers often find themselves within residential care services as family based care is no longer an option due to increased behavioural episodes and limited supports provided to the foster carer to manage and stabilise the placement. High levels of placement instability result in young people being placed in High Cost Placements often with 1:1 or (2:1) 24/7 youth worker support. Living in an environment that is characterised by revolving shift workers is neither normal nor healthy for young people. High Cost Placement could be avoided and better placement stability could be achieved, if children and young people are provided an appropriate placement option in the first place, and carers are supported to provide for the needs of the child or young person.

**Recommendation 11**
Investment in systems to ensure appropriate matching of children and young people with the appropriate care environment, and ensure that adequate supports are put in place to achieve stability of the placement.

#### SECTION 3: TRANSITIONING OUT OF CARE

### 3.1 Risks for Young People with a Disability

Transitioning out of the care system presents risks for all young people, many of whom experience difficulties with lack of familial support, no ongoing support from foster carers or other care providers, little access to ongoing support, and limited emotional, financial, social and interpersonal resources. It is known that histories of abuse and neglect, removal from biological families and

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multiple placements in out of home care can result in young people being ill prepared for the transition to adulthood.\textsuperscript{24}

Although awareness is growing about the challenges facing young people transitioning from care, the outcomes for those with a disability have often been ignored.\textsuperscript{25} Research literature reports that young people with a disability who are not in care have difficulty coping with development and situational transitions. This is due to poverty, less well developed coping and social skills, greater dependence on others, behavioural issues hindering integration and acceptance, family stress, social barriers, limited employment options and inadequate service provision.\textsuperscript{26} The experience of living within the Child Protection System, as well as having a disability, compounds these issues.

Research conducted within Queensland\textsuperscript{27} and internationally\textsuperscript{28} has determined that the recurring disadvantages experienced by young people with a disability leaving care include:

- Homelessness
- Drug or alcohol abuse
- Poor mental and physical health
- Poor educational outcomes
- Poor employment opportunities
- Poor social support
- Juvenile prostitution
- Crime and contact with the justice system
- Early parenthood
- Exploitation and victimisation
- Isolation

Limited opportunities and a history of dependency inhibit the development of skills that young people require to live successfully as adults. Young people with a disability who encounter systemic and attitudinal barriers to establishing themselves as adults “are more likely to experience defeat leading to feelings of low self-esteem, inadequacy, depression and hopelessness”.\textsuperscript{29}

Young people with a disability transitioning from care fall into two categories: those who transition from Child Safety to Disability Services, and those who are not eligible for ongoing financial support and are required to find their own accommodation and supports. Those transitioning from Child Safety to Disability Services experience a reduction in supports as a result of the reduction in available funding. In some cases support models move to 1:1 support where a 2:1 model was previously in place. This can place both the person with a disability and their care workers at risk of harm.

On exiting care, many young people who are not eligible for funding have no choice but to return to dysfunctional, abusive or neglectful families who are ill prepared to support them. This reunification

\textsuperscript{24} Schormans, A. & Rooke, J. (2008). When there are no choices: The consequences of a lack of adult living placements for young adults with intellectual and/or developmental disabilities leaving child welfare care. \textit{Journal on Developmental Disabilities, 14}(1), 107-126.
\textsuperscript{26} Schormans & Rooke, 2008.
\textsuperscript{28} Geenen et al., 2007.
\textsuperscript{29} Schormans & Rooke, 2008.
often fails and the young person may be at risk of homeless or transience. It is Endeavour’s experience that young people with a disability take longer to settle and develop the regulatory patterns, skills and resilience that allow them to live well as adults within our community. Therefore, we recommend that the leaving care age for young people with a disability be raised to 25 years.

**Recommendation 12**
Extend support for young people with a disability in care to 25 years to better prepare them for adulthood and the challenges of transitioning out of care.

**CONCLUSION**

Endeavour Foundation argues an integrated child protection system that includes universal, primary, secondary and tertiary responses designed to support families caring for a child with a disability will provide better outcomes for children and their families.

All children and young people with a disability face disadvantages and barriers to living a full life. Those children and young people who come into contact with the Child Protection System face the same barriers at a much greater intensity. The loss of family, lack of consistent care and compounded trauma is leaving these young people exposed to major disadvantage. It makes good social and financial sense to invest early in supporting families and their children to avoid the long term costs to society and individuals.

**SUMMARY OF RECOMMENDATIONS**

1. Endeavour Foundation urges the Queensland Government to support the implementation of a national NDIS.

2. Establish a Case Management program where a child diagnosed with a disability is appointed a Case Manager responsible for life-time planning and identifying family support needs to support family preservation.

3. Develop an early intervention strategy and programs that target families with children with a disability (across all age groups) to ensure the necessary supports are in place to preserve children living with their families.

4. Develop a secondary response system that can identify families under stress and provide additional supports to prevent relinquishment.

5. Develop a culturally appropriate early intervention service model that is grounded in cultural identity, community development and capacity building to support communities to respond locally.

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6. Establish a referral pathway for children with a disability entering the Child Protection System that ensures the child is provided with adequate supports through specialist disability service organisations.

7. Reliable and accurate data systems need to be developed that provide information state-wide and regionally on the disability of children and young people known to the Child Protection System, either as a risk of entering care or already in care. This data needs to be available to service providers attempting to respond to this vulnerable population.

8. Expand the Specialist Response Foster Care Model in order to meet the needs of children and young people with a disability who are assessed on the complex to extreme spectrum.

9. Intensive Foster Care be provided to children and young people living with a disability who are assessed on the mild to moderate spectrum.

10. Review and develop a residential care model that supports the needs of young people with a disability together with the necessary expertise and qualifications required from staff.

11. Investment in systems to ensure appropriate matching of children and young people with the appropriate care environment, and ensure that adequate supports are put in place to achieve stability of the placement.

12. Extend support for young people with a disability in care to 25 years to better prepare them for adulthood and the challenges of transitioning out of care.

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