

A stylized graphic of a human figure on the right side of the slide. The figure is composed of a solid blue circle for the head, a thick blue line for the torso, and several curved, overlapping lines in shades of blue and green for the arms and legs, suggesting movement and support.

# **UNCOVERING DISABILITY: Supporting Children and Young People with Disability in out of home care**

**Presenter: Lyn Ainsworth**

# Who is ACWA?

The Association of Children's Welfare Agencies (ACWA) is a key NSW peak body representing the voice of non-government community organisations that deliver services to vulnerable children, young people and their families.

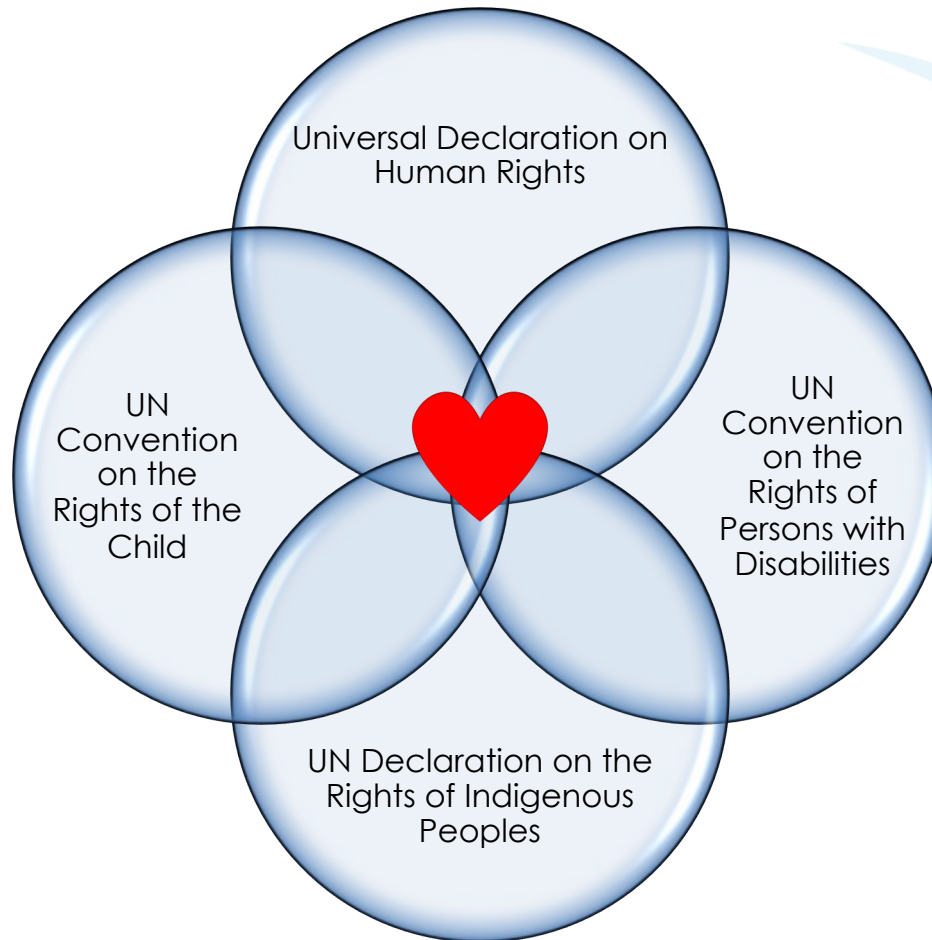
Established 65 years ago, ACWA has worked with members, partners, government and non-government agencies, and other peak bodies including AbSec, to bring about positive systemic reform to deliver better outcomes to the lives of vulnerable children and young people, including those living in out-of-home care by:

- Advocating for the rights, needs and interests of vulnerable children and young people
- Providing sector leadership – gathering knowledge, examining new concepts and promoting best practice
- Providing flexible and tailored training through the Centre for Community Welfare Training (CCWT).

# Who am I?



# What this talk is really about ...



## Human Rights

# If we take a Human Rights approach ...



We will DO the  
RIGHT THING

Get things  
RIGHT

(mostly)

# ACWA's Disability Project

“Falling through the gaps?”

Ensuring the best outcomes for vulnerable children and young people with disability

Through this project we set out to better understand the nature of the challenges experienced by providers, causative and contributive factors and identify practical solutions to ensure that children with a disability / potential disability get the best possible supports, including access to NDIS.

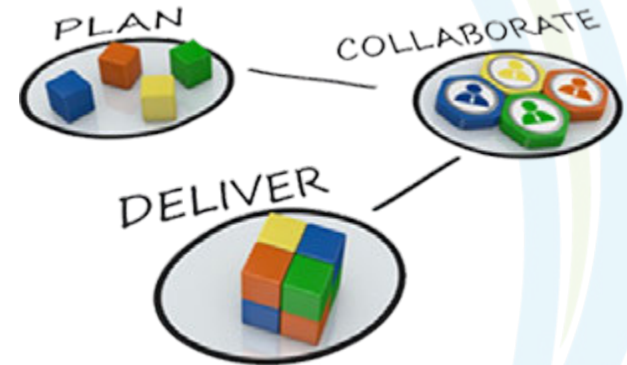
- Stage 1 – Research
- Stage 2 – Action



- *Full & Summary Reports: Available on ACWA's website: [www.acwa.asn.au](http://www.acwa.asn.au)*

# Engaging, listening & learning

- Conversations with a large number of providers to identify the key issues and challenges, at the same time recognising innovative and creative ways that agencies are addressing the issues.
- Engagement with a broader group of stakeholders
  - AbSec
  - VALID
  - Create
  - IDRS
  - Youth in Action
  - My Forever Family
  - Professor Sally Robinson
  - VOOHC providers
  - NSW Ageing and Disability Commission
- A survey reflecting the issues, causative factors and potential responses completed by 21 stakeholders.
- Crystallisation of key areas for further investigation (inter-related):
- 12 workshops focusing on the key themes and including potential actions in response.



# Outcomes against Objectives #1

## Objective 1

To undertake analysis in relation to children and young people in out of home care to assess:

- The incidence of children and young people with a diagnosed disability within this group
- The potential extent of undiagnosed or under-diagnosed disability within this group of YP
- The nature and scope of NDIS packages and plans currently in place, and the adequacy of those plans to meet individual needs
- The potential opportunity for other children and young people to access supports through NDIS packages
- Barriers and challenges to children and young people and their carers being able to effectively access the NDIS
- Levels of awareness and knowledge of carers and staff of NDIS and agency processes
- Looking at those causative factors, consider potential opportunities for enhancing support for these young people.



There are already **many** children in this group who have identified / diagnosed disability.



There is a potentially **high incidence** of children young people with undiagnosed, or under-diagnosed disability – estimates of 30-50%.



Providers reported that for those children who had an **NDIS** package, many were considered **inadequate** or **under-utilized**.



There appears to be **significant opportunity**, particularly in EI. There needs to be a greater focus on Leaving Care. There may be a need for supports other than NDIS. There are multiple **challenges!**



There are **many**. Refer to survey insights summary. There are big **gaps and variance** in the understanding of disability amongst staff in OOHC. Similarly, there is very limited awareness of the OOHC environment amongst those implementing NDIS (agency staff, planners, Support Coordinators)



The **next steps** in the Project: to develop clear **recommendations** from the wisdom collected to date





# Outcomes against Objectives #2

## Objective 2

Based on the analysis undertaken in connection with Objective 1, ACWA will work with key stakeholders on identifying and implementing enhancements to practice, to deliver improved outcomes for children and young people with disabilities in out of home care.

*Given the high incidence of Aboriginal children and young people in out of home care, particular consideration will be given to this especially vulnerable group.*



*The core purpose of the project is to identify practical pathways, initiatives, tools, training and other resources that enhance sector capability and practice in this important area, ensuring the best outcomes for vulnerable children.*

### Opportunities:

- Advocacy & lobbying (multiple platforms)
- Hearing from young people with lived experience
- Greater engagement with Aboriginal agencies and communities
- Training and support for staff, carers, NDIA
- Specialist roles (funded)
- Communities of practice – broad engagement
- Biannual sector meeting with DCJ / NDIA to engage, enhance
- Inform data collection & assessment processes
- Research to monitor the impacts of good practice and outcomes

# To achieve these core outcomes:

## Children and Young People:

Vulnerable children and young in out of home care arrangements who have / may have a disability are identified early and are provided with the supports they need to achieve the best life outcomes



## Providers

OOHC Providers can effectively engage and collaborate with policy and decision makers and be respected and recognised for their expertise for their contribution.

## Workforce

The employees and carers across the sector are knowledgeable and confident, well-equipped and well-supported to effectively support the most vulnerable of our young people.



# Themes that emerged

Key finding:

*It appears there is a high incidence of disability amongst CYP in OOHC, potentially 30-40%, many of whom are falling through the gaps, without adequate diagnosis and / or access to specialist disability support.*

Issues identified as contributing factors and opportunities for enhanced practice:

1. Intake processes, assessment and information about a CYP
2. Workforce and carer knowledge and capacity in supporting CYP with disability
3. NDIS systems and processes: barriers and insights
4. Intersections with other systems: Child protection, disability, health (and mental health), education, youth justice
5. **Cultural considerations in supporting the needs of CYP with disability:**
  - a) **First Nations CYP**
  - b) **CALD CYP**
6. Transition points – particularly leaving care

**We need to hear the voice of children and young people.**

# Supporting vulnerable First Nations children and young people with disability

Commitments Australia has made ...

## United Nations Declaration on the Rights of Indigenous People (UNDRIP)

The Declaration establishes “*minimum standards for the survival, dignity and well-being of the indigenous peoples of the world*” noting at Article 22 that “*Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with a disability.*”

## United Nations Convention on the Rights of the Child (UNCRC) – Article 30:

“*A child ... who is Indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her culture, to profess and practice his or her own.*”

## United Nations Convention on the Rights of the Persons with Disabilities (UNCRPD) – Article 7: Children with Disabilities

**Article 30:** “*A person with disability shall be entitled on an equal basis with others, to recognition and support of their specific cultural and linguistic identity.*”

# ACWA's Project identified:

- Many issues shared by all First Nations CYP in care – but amplified by disability
- Disproportionate representation of Aboriginal CYP in care *coupled with* over-representation of disability
- Lack of understanding of critical cultural concepts of “wellbeing”, “safety”, disability
- Lack of culturally appropriate / responsive services
- Inadequacy of cultural planning
- Insufficient indigenous workers and carers
- Inadequate knowledge across the workforce of both disability, culture and the intersection between.
- And the list goes on ...

# What is required?

*“Connection to culture is crucial for our children to develop their own sense of identity, connection and belonging.” (Family Matters Report 2020)*

Listening

Leadership Commitment

Resources

Investment

Trust

Collaboration & coordination

Capacity building

Focus on each individual child



# Approach to outcomes:



**PHILOSOPHICAL** – Identifying apparent misalignment between human rights, policy and implementation.

**PRACTICAL** – What can we do to create positive change for the benefit of the children and young people at the heart of the system?

**POSITIVE** – We want to make a difference, build constructive, not adversarial, relationships with shared accountability.

**PROACTIVE** – We can't wait. We need to create a sense of urgency and be part of the solution.

**POSITION** – ACWA wants to create a compelling narrative to support the platform for improvement.

Underpinned by **PASSION** for the work we do.

# Response: A collaborative action plan

Focused on:

- Recognising the vital importance of collaboration: ACWA, AbSec, DCJ
- Building sector knowledge and workforce competence, confidence and capacity
- Engagement with the NDIA
- Hearing the voice of children and young people
- Advocacy and policy



# The voice of children and young people



**Forum with CREATE Foundation: 9 participants, including 1 online. 4 female, 5 male. Aged 24-27. 2 First Nations. All care alumni. A range of disabilities – physical, intellectual, psychosocial and mental health.**

## **Focus:**

1. A human rights view
2. Ability - not disability
3. What ideas do we have that could make the system better, meaning a better experience for young people with a disability in out of home care.

# What the young people told us:

## What are some of the challenges faced by a child or young person with a disability who is in out of home care?

- Bullying, discrimination & disrespect
- Disability not identified or not explained
- Poor treatment
- No intervention until a “crisis” point - by then it is too late
- Challenges relating to being able to express yourself due neurological / developmental issues.
- The system only acts when a person speaks out – but in many instances a young person with disability is unable to speak out, and has no-one to do that for them.
- Getting a diagnosis can be difficult
- There is a lack of interaction and cohesion across the matrix of systems in which the young person needs to operate
- Engagement with the individual is superficial – “they don’t really care”.
- Disempowerment: Not allowed to make decisions
- Intergenerational
- Lack of accountability “at the top” of service provider organisations.
- Inadequate resources available to carers.
- Lack of connection to culture The system lacks any real lens on culture or disability. This is a significant disadvantage for a young person who experiences both.
- Lack of commitment to family finding. “It doesn’t matter.”
- Patronised for having a disability.

## What can be done to make the system better?

- Get the Premier and politicians to listen - Listen to us, reply and act.
- Increase case worker support.
- “Rebuild the system”
- Need case workers with knowledge of disability and disability support workers as part of the team.
- Labels of disability – a single labelled applied without considering the nuance / difference between types of disability and how it might affect each individual (Autism is a good example.)
- Professionals within other interdependent systems also need knowledge of disability – especially schools.
- Community attitudes, knowledge and understanding needs to change – be more inclusive.
- Disability specific section in DCJ, to advocate Improvement of NDIS Support Coordinators
- Changes in NDIS processes
- Need people who believe in you – your ability, not just see your deficits.
- Develop ways to enable young people with a disability to speak up about what they need.
- Inclusive attitudes – don’t judge or make assumptions
- More education about disability across a range of professions especially educators. Helping them to understand the rights of a person with disability.
- Support post 18yo – until “settled”

# What they said needs to be done:

- Address issues of accountability in the system
- We need to see real change – ACTION – not just words, in relation to systems, carers and workers and perceptions of disability
- Need for staff / carer training and adequate funding for young people – to ensure that even basics are covered
- A special agency / department to oversee – including autism specific expertise
- An information line available to young people to assist in navigating systems
- Need to ensure access to adequate and appropriate staff to ensure that young people with a disability feel safe and comfortable with their carers.
- ***The situation is critical – get on with fixing it!***
- ***Know people as people first.***
- Ensure awareness and access to available concessions (eg prescriptions) – don't keep up with cost of living increases.
- "I just want to have a good life."
- Access to advocacy. Help to become knowledgeable about rights and supports.
- Need for specific focus on babies in long-term hospital care – ensuring they have a family history, photos and are acknowledged as a person
- Leverage the Disability Standards in education (eg for University access)
- Need for mental health support post adoption – for child and adoptive parents
- Support for the feelings of young people with a disability (and others) – reassurance and support – rather than being made to feel they are at fault for what happens. Need a sense of safety and value.
- A place to connect with others with shared experience – camp, respite, activity centre.

# Work that has been undertaken

- Establishment of Disability Community of Practice
- Webinars and interactive workshops for practitioners in conjunction with disability specialist partners, ACWA members and NDIA
- Workshop forum in partnership with CREATE - young care leavers with disability have their say
- Workshops for Carers
- Advocacy and information
- Connection to other ACWA projects (Leaving Care, Carer Recruitment, Sector Development, Data)
- Contribution to this forum
- Linkages to other research, advocacy agencies and stakeholders
- Building resource library
- ACWA Good Practice Symposium last week

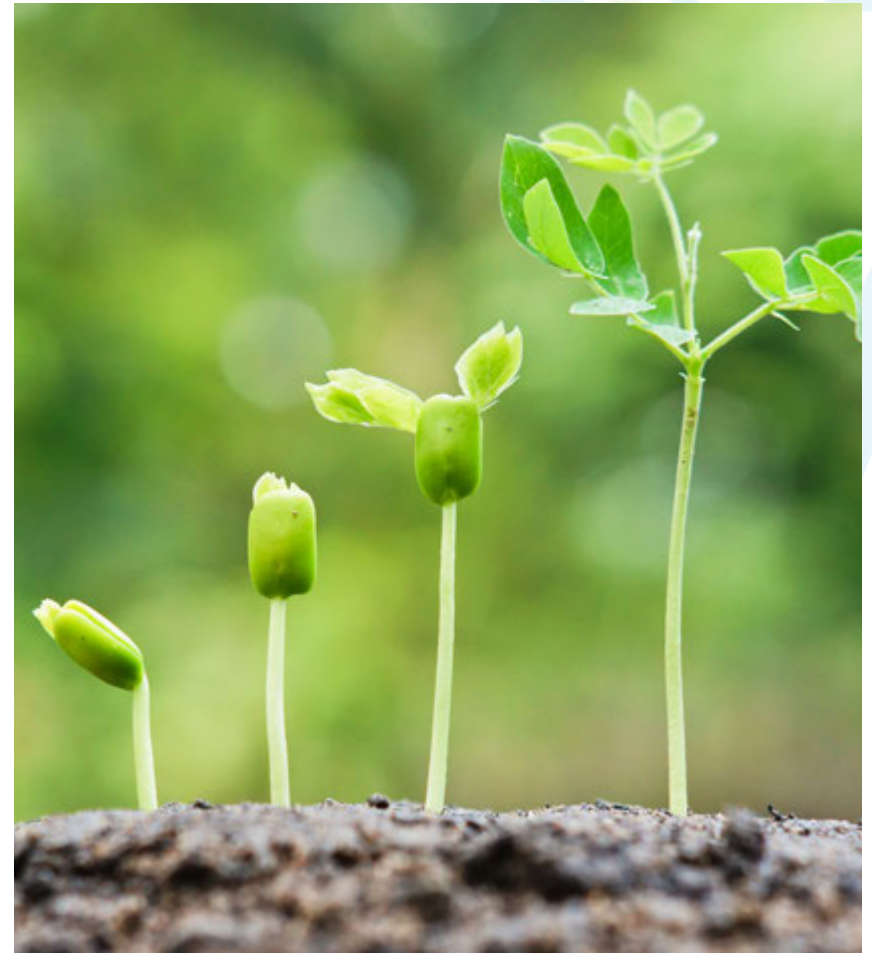
# What's happening across the sector & beyond?



- Specific inclusion of kids with disability in PSP contracts
- DCJ Engagement & Family Support Team within OSP
- Transition of First Nations children and young people in care to ACCOs
- Aboriginal Outcomes Team
- Family is Culture work
- The VOICE referendum

# What's next?

- What do we need to do together?
- Research?
- A cultural lens across the system – reducing children coming into care and improving outcomes for those in care
- ACWA is committed to supporting AbSec's leadership in this area.



# Question Time

