Wills Guide

Give the gift that allows us to stand up for generations to come.

DOWN SYNDROME
NEW SOUTH WALES

“I remember feeling really lonely in those early weeks. Turns out, having a child with Down Syndrome has been anything but lonely as I’ve been plugged in to the most wonderful community of people who have either been there before you or are experiencing alongside you the joys and puzzlements of raising a child with an extra chromosome. Anything you are wondering about, there is someone out there to offer advice, ideas, and friendship to help you and your child. You are not alone, even if it feels like it right now. I found Down Syndrome NSW was the best place to start our new journey.”

– Louise, Mother to Theodore

About Down Syndrome NSW

In 1980 in NSW, Australia, there was a remarkable group of individuals who had children who were born with Down syndrome. Inspired by their children's journey and fuelled by their desire to create a more inclusive society, the parents embarked on a mission to establish an organisation dedicated to supporting individuals with Down syndrome and their families. And so, the seeds of Down Syndrome NSW were sown.
As the word spread, more families joined these gatherings, forming a tight-knit community that offered support, understanding, and hope.

The parent group worked tirelessly to run programs and collaborated with healthcare professionals, educators, and community leaders to raise awareness about Down syndrome and advocate for improved services and opportunities.

With the growing momentum, Down Syndrome NSW vision expanded beyond support groups and advocacy. They envisioned a dedicated organisation that could provide a wide range of services to individuals with Down syndrome, from newborn babies right through to support for the aging. With the help of passionate volunteers and the backing of the community, Down Syndrome NSW began to take shape.

Today, Down Syndrome NSW continues to evolve and adapt to the changing needs of the community. We have become a catalyst for change, breaking down barriers and championing the rights and abilities of individuals with Down syndrome. These parents and their story stand as a testament to the power of compassion, determination, and the enduring spirit of individuals, who make a profound impact on the world by turning their dreams into reality.

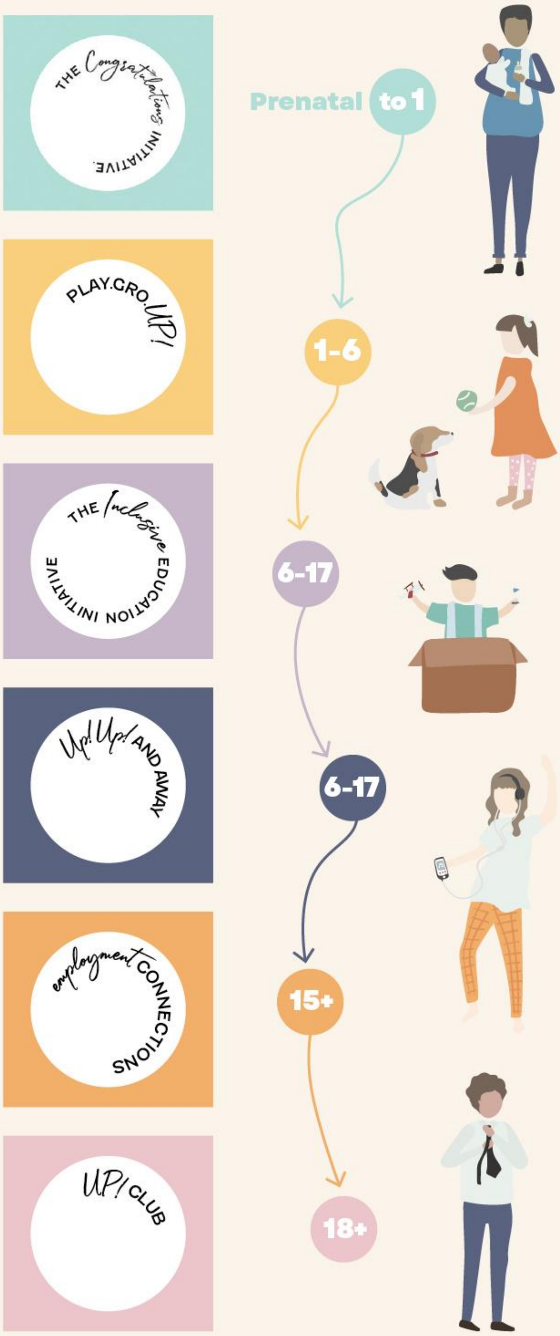
> “Before this, I didn’t even know Down Syndrome NSW existed but I will be forever grateful as the first thing they said to us upon entering our hospital room was, “Congratulations!” She then spoke about her experience as a mum of a child who has Down syndrome and totally normalised the whole situation for us.”
>
> – *Melissa, Mother to Alyssa*

DOWN SYNDROME
NEW SOUTH WALES

Our Vision

All people with Down syndrome live meaningful lives as valued and contributing members of their vibrant, inclusive and diverse communities.

SERVICES & SUPPORTS



THE Congratulations INITIATIVE — Prenatal to 1

PLAY.GRO.UP! — 1-6

THE Inclusive EDUCATION INITIATIVE — 6-17

Up! Up! AND AWAY — 6-17

employment CONNECTIONS — 15+

UP! CLUB — 18+

CAPACITY BUILDING

THE Inclusion INSTITUTE

- Conferences
- Workshops
- Fact sheets
- Stories
- Toolkits
- Resources

- Policy
  National & State
- Advocacy
- Submission
- Research
- Consultations
- Library
- Online Training
- Workforce Capabillity
- Community Awareness

DOWN SYNDROME
NEW SOUTH WALES

Our Impact

THE Congratulations INITIATIVE

100%

of new parents said
that our New Parent Packs and
hospital/home visits were helpful

130 medical professionals attended our in-services

Average evaluation rating of Medical
Professionals Information Pack and
In Service

★★★★⯪

100%
recommend our
Medical Professionals
Information Pack and
In Services

Requests for more training,
information, resources and
support:

100% yes

Up! Up! AND AWAY

30 people attended our Up! Up! and Away events

1 event was facilitated by one of our celebrity ambassadors

employment CONNECTIONS

27 people with Down Syndrome placed in employment

51 employers engaged and upskilled on inclusive employment

UP! CLUB

238 capacity building activities held per year

3 camps per year with **150+** participants

THE Inclusion INSTITUTE

68 workshops held

1,634 participants attended

Our Impact in the Past Year

76 events + workshops

283 community activities

19 policy submissions

4.2 star average rating for events + workshops

4 star average rating for satisfaction with DSNSW

34 consultations conducted

79 government and interagency meetings

1,791 social media posts

42 new partnerships + ambassadors

31 memberships to national, international and local peaks

21,072 emails + phone support

81 new resources developed

83% of staff have lived experience of disability

7 new programs implemented

Leaving a lasting legacy

We hope that when you create or update your Will, you will consider including a gift to Down Syndrome NSW

A significant proportion of our funds donated by individual members of the public come from bequests. We depend on this vital source of income to run our programs.

Knowing that we can depend on future income from bequests gives us financial security. We can plan ahead for our programs, knowing that we'll have the donations we need to make them succeed.

Ultimately, gifts in Wills help us ensure that we'll be around long into the future, supporting people with Down syndrome and their families

How to leave a gift to Down Syndrome NSW

To leave a gift to Down Syndrome NSW in your will, you can follow these steps:

1. Consult with a solicitor:

They will guide you through the legal process and ensure your intentions are properly documented.

2. Determine the Type of Gift:

Decide on the type of gift you would like to leave to Down Syndrome NSW. There are a few options you can consider:

- Estate Bequest: This involves leaving a percentage or a portion of your estate. Just 1%, 2% or 5% can make a huge difference
- Pecuniary Bequest: This involves leaving a specific monetary amount to Down Syndrome NSW
- Specific Bequest: This involves leaving a particular asset, such as property, shares, or personal belongings, to Down Syndrome NSW

3. Contact Down Syndrome NSW:

Contact Down Syndrome NSW to express your intention of leaving a gift in your will. They can provide you with the necessary information and guidance to ensure your gift is directed to your preferred programs or initiatives within Down Syndrome NSW.

4. Review and Update Regularly:

It's important to review and update your will periodically, especially if there are any changes in your circumstances or wishes. Keep your solicitor informed about any modifications you wish to make.

5. Inform Your Loved Ones:

Communicate your desire to leave a gift to Down Syndrome NSW with your loved ones. This will help ensure your wishes are understood.

Recommended wording for your Will

If you wish to donate a percentage of your estate after providing for loved ones -

“I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, _____ % of my residuary estate for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee.”

If you wish to donate what’s left over of your estate after providing for loved ones -

“I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, the whole of the residue of my estate for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee.”

If you wish to donate a specific sum -

“I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, the sum of $_____ for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee.”

If you wish to donate a specific item -

“I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, my _____ for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee.”

Down Syndrome Angels

By leaving a gift to our work in your Will, you will join an honoured group of supporters within the Down Syndrome Family: Angels.

Together, the Angels are shaping a world where members have somewhere trusted and safe to turn for help, comfort and support, no matter what. You will share in our achievements, connect with inspirational people and be part of our story.

We celebrate our Angels today, and every day, for the hope that they inspire in our collective ‘tomorrow’.

We are so grateful for their commitment, and we hope one day to welcome you.

Our Promise

We will handle whatever gift you leave us efficiently, so that it can do the greatest good in the areas where it is needed most.

We will ensure your gift goes to the exact program, initiative area you specified in your Will

You have every right to change your mind about a gift in your Will at any time.

Any information you share with us will be kept strictly confidential and will be used respectfully and appropriately.

Our Stories

DOWN SYNDROME
NEW SOUTH WALES

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Christopher Jones’ Story

HEALTH AND WELLBEING

Born with Down syndrome, Christopher’s path was marked by medical complexities from an early age. At just seven months old, he underwent open-heart surgery to address congenital heart disease, a pivotal moment that would shape his family’s journey. Over the years, Christopher encountered various health challenges, from epilepsy to Graves’ disease, each hurdle met with courage and determination.

Through the highs and lows of Christopher’s medical journey, the Jones family found solace and guidance in the supportive embrace of Down Syndrome NSW. Their newsletter, a beacon of information and insight, evolved over the years to become a lifeline for families like theirs. Lily, Christopher’s devoted mother and tireless advocate, found herself empowered by the wealth of knowledge and resources provided by the organisation.

As Christopher navigated the complex landscape of healthcare, his experiences underscored the importance of communication and understanding. Simple gestures, like medical professionals directing questions at him and allowing ample time for responses, made a world of difference. Christopher’s advice to doctors and caregivers echoed the sentiment of inclusivity and empathy, urging them to modify language and engage with patients in a meaningful way.

Amidst the challenges, Christopher’s spirit remained indomitable. His resilience, coupled with the unwavering support of his family and the broader community, propelled him forward. With each milestone, Christopher defied expectations and shattered stereotypes, proving that a diagnosis could never define the breadth of his potential.

> **Through it all, Lily stood as Christopher’s fiercest advocate, her unwavering love and dedication guiding their family through every twist and turn. Her contact information, a lifeline for those seeking support and connection, symbolised the strength of their bond and the power of community.**

Down Syndrome NSW emerged as a steady anchor, offering support, resources, and a sense of belonging. Their impact transcended mere information; it was a beacon of hope, empowerment, and advocacy for families like the Joneses, inspiring them to embrace Christopher’s journey with courage and conviction.

Melissa and Alyssa's Story

PRENATAL AND NEW BABY

Melissa is the Down Syndrome NSW Up Up & Away Coordinator and Information & Support Officer. She is also mum to 4 beautiful girls including 16 year old Alyssa who has Down syndrome. She shares her story to inspire and encourage others.

"I was once showing Alyssa a video of a group of mums singing a beautiful song with their children who have Down syndrome. All of a sudden, Alyssa had tears in her eyes and asked me to stop the video. I apologised to her, thinking the video had upset her and asked if they were happy or sad tears? She told me they were happy tears because she loves her name, Alyssa, and that she's glad she's my daughter. She added that she feels so special and loved by our family and expressed the beautiful memories she has of us singing just like the children in the video. We hugged and cried happy tears together.

I feel so blessed that Alyssa can articulate her deepest feelings and tell me that she knows she is loved.

I want to share my story to show how wonderful the journey of raising a child with Down syndrome can be and the importance of support from day one!

Alyssa was born on 16th May 2006. We discovered she had Down syndrome (Trisomy 21) shortly after. I didn't know anything about Down syndrome, but I did know I loved my baby very much and wanted to do all I could for her.

A lovely nurse came into our hospital room and gave me an information pack from Down Syndrome NSW and offered to arrange a visit from a parent support team member at Down Syndrome NSW. This visit was the most amazing, supportive and informative welcome to the Down syndrome community my husband Michael and I could have asked for.

Before this, I didn't even know Down Syndrome NSW existed but I will be forever grateful as the first thing they said to us upon entering our hospital room was, "Congratulations!" She then spoke about her experience as a mum of a child who has Down syndrome and totally normalised the whole situation for us.

Just seeing her talk so candidly, lovingly and kind to us gave us strength and tremendous hope for the years ahead.

She also talked about her daughter, who was twenty something at the time and her sense of humour. It was so reassuring. She also told us of all the information and supports Down Syndrome NSW offers, supports that I now get to provide in my role with all of my own lived experience to guide me!

In a world that can view the anomaly of having an extra copy of Chromosome 21 as not being worthy of life, holding my baby and having this hospital visit squashed society's understanding of normal. Alyssa is our normal and our kind of perfect, she's changed our lives for the better. 16 years into this journey I can honestly say it's been a beautiful one. Yes, parenting has its challenges (we have four beautiful children) and I don't always get it right as a mum... but they are all people first and I've learned that love can get you through any challenge."

Our Stories

DOWN SYNDROME
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Charlie's Story

INCLUSIVE EDUCATION


Mudgee

MUDGEE

Congratulations

Charlie Swords

on the completion of your first year of school

Charlie was the first child with Down syndrome to attend his local school in a small regional town in NSW. It wasn't an easy start. Initially, his parents were encouraged to check out the 'special/support unit' at the public school instead, where most of the children with Down syndrome had historically been directed. This is the message parents like Pearl & Adam so often receive from schools with only the best intentions: your child doesn't really belong here, try somewhere else.

But Charlie's parents were prepared for this response and were able to provide the school with evidence-based data to support their decision – and gratefully, the school accepted Charlie.

Over the years, Pearl and Adam worked collaboratively with the school, willing to try new approaches, equipping new teachers with supporting notes and ensuring the values of his school were embedded at home too.

Today, Charlie loves going to school and has maintained meaningful, long-term friendships along the way. His teachers and aids have been exceptional in the support they've provided, providing regular and open communication and offering multiple planning meetings at the start of each school term. Despite the school's early reluctance to take Charlie on, there's been a significant shift in mindset, and Charlie's community has come to recognize and celebrate the valuable role he plays in the community.

The message they receive from his school now? 'Thank you for gifting us with Charlie's presence.'

Without accurate research and information, many schools would not so warmly welcome children like Charlie, assuming that his needs couldn't be met in a conventional schooling environment. Here, at Down Syndrome NSW, we see our role as vital in supporting parents like Charlie's to have these difficult conversations with schools, change the narrative surrounding children with Down syndrome and stand behind their choices for inclusive education. For Pearl and Adam, inclusive education means no child gets left behind, and we're committed to making that vision a reality.

"It is just wonderful to know that Emily and her incredible team are doing their utmost to support our kids in all aspects of life stages. Their commitment to research, innovation, collaboration and education/support for all involved is incredibly reassuring and inspiring." – Pearl & Adam

Our Stories

DOWN SYNDROME
NEW SOUTH WALES

Sam Stubbs' Story

HOME AND LIVING

Moving out of Home

Sam's journey towards moving out of home began in August 2022 at Down Syndrome NSW's empowering Housing Conference. Surrounded by support and guidance, Sam left with a newfound determination to venture out on his own, away from the easy comforts of home and the watchful eyes of his parents.

With unwavering encouragement from his family and the invaluable resources provided by Down Syndrome NSW, Sam embarked on a mission to find his own place. After careful planning and scouting, they discovered a perfect home just a stone's throw away, where Sam could spread his wings while still being within reach of his loved ones.

Following the Supportive Housemate model, two flatmates were found, and Sam transitioned seamlessly into his new abode at the age of 24, a milestone celebrated with pride by his family. The sense of achievement was palpable as Sam embraced this new chapter of his life with confidence and grace.

Six months later, with Sam settled comfortably into his routine, his parents embarked on a well-deserved holiday, reassured by the robust network of support they had established. Through meticulous planning and the assistance of dedicated caregivers, they could finally enjoy a vacation, knowing Sam had a great support network around him

Ongoing monthly house meetings have been a cornerstone of their arrangement, providing a platform for open communication and problem-solving. With Sam at the centre of discussions, along with his supportive flatmates, family, and caregivers, they tackled challenges head-on, ensuring a harmonious living environment for all.

Reflecting on their journey, Sam's family shared invaluable advice gleaned from their experience. They emphasized the importance of building a strong support team, reaching out for assistance, and fostering reciprocal relationships with his flatmates, neighbours and friends. Practical tips, such as organizing household services and maximizing available funding, underscored their commitment to Sam's well-being.

Sam himself offered simple yet profound advice: "Just do it. You will love it!" His unwavering optimism and courage served as inspiration for others considering this important rite of passage.

Creating a Brighter Future Together

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