



Impact Report 2013



7,500 young people with high care needs are living in aged care facilities.
(National Disability Agreement 2010)



700,000 are being cared for at home by loved ones, often with limited support.
(Australian Institute of Health and Welfare 2007)

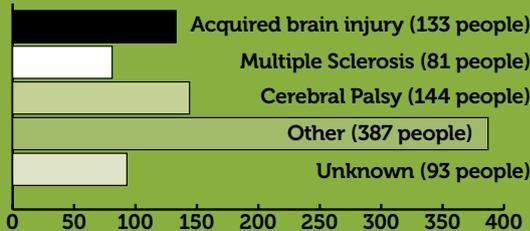
Youngcare Connect

838 new client contacts in 2012-13, an average of **70** new client contacts per month

An average of **30%** of all calls resulted in a referral to relevant state and territory disability services, organisations and community based not for profit organisations

26% of calls were residential requests for Youngcare Apartments, respite and enquiries for other accommodation options

Type of disabilities



Events, fundraising & community support

\$1 million+ raised through Youngcare events



1200+ event attendees & participants at Youngcare events

\$325,000+ raised through community & beneficiary events

245+ registered volunteers across Australia

\$350,000+ raised through fundraising appeal activities

Reach through Media (TV & print)
TOTAL: 28,175,062

Reach through Facebook
TOTAL: 2,547,706+

Land granted TOTAL: 5,230m²

At Home Care Grants

Since 2009 **over \$1 million** has been granted to 217 recipients

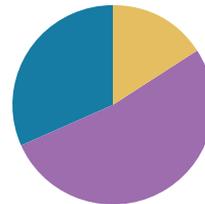
112 grants were distributed in 2012-13

Across all four grant rounds in 2012-13, a total of **\$550,000** was made available yet \$2,352,000 was requested

Granted Total requested \$

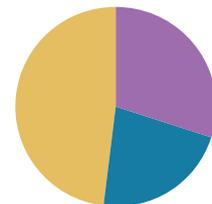
Over 4,900 hours of respite granted

Queensland funding allocation
October 2012



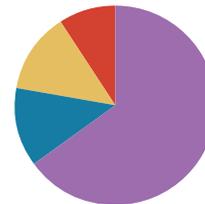
105 applicants
totalling \$742,984
19 successful

Victoria funding allocation
February 2013



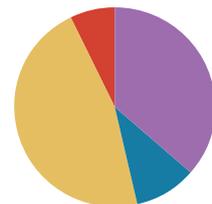
62 applicants
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Queensland funding allocation
March 2013



64 applicants
totalling \$391,064
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NSW funding allocation
April 2013



106 applicants
totalling \$747,372
30 successful

Equipment Home modifications Respite Other

Government engagement

Met with **40+** state and federal parliamentary members across Queensland, New South Wales & Victoria

Met with all disability centric politicians in Government at all levels

Two Youngcare residents co-authored a National Disability Insurance Scheme Submission which was presented to the NDIS Senate Committee hearing in Canberra in March



The Year That Was

This year saw Youngcare take great strides in raising awareness about the issue of young people in aged care, providing support and assistance to young people with high care needs and their families, and continuing research into a replicable and viable model of care and housing.

Highlights

- The future for young people with high care disabilities and their families will change forever when the National Disability Insurance Scheme (NDIS) was legislated. The reform will revolutionise the entire Australian disability system
- Earlier in the year, Youngcare was successful in its bid for a \$1 million capital funding grant under the Queensland Governments Elderly Parent Carer Innovation Trial
- Youngcare successfully secured land from the Queensland Government in Woolloowin to build two new Youngcare building innovations: firstly a four bedroom share-house, which will look to challenge common issues associated with resident privacy and choice in housemate selection. The second part of this project will consist of co-located family homes which will offer another option which aims to keep family units together while providing high care support
- Youngcare prepared a submission in response to the National Disability Insurance Scheme (NDIS) Bill 2012, in conjunction with two Youngcare residents. This submission was then presented at the NDIS Senate Committee hearing in Canberra in March
- The one millionth dollar was distributed through the Youngcare At Home Care Grants program since beginning in Queensland in 2009
- 112 young people helped via the At Home Care Grants program
- Youngcare At Home Care Grants were launched in Victoria, with \$100,000 distributed to 23 young people with high care needs



Premier Newman announcing the Woolloowin land grant

- New five year strategic plan developed and rolled out
- Youngcare entered into new partnerships, formed to help create more solutions for young people with high care needs.
- New additions to the Youngcare Board that have helped to widen the skill base and enable Youngcare to achieve its vision in new and exciting ways
- Youngcare began work on the 'Social Investment strategy' engaging key players such as KPMG, Social Ventures Australia and Foresters Community Finance
- Youngcare launched the Chairman's Circle in partnership with UQ Business School
- Youngcare Connect phone service expanded nationally with a new person employed in NSW

Please know that through your ongoing support, you have enabled Youngcare to achieve these highlights, as well as many more possible.

Our message to you

From Youngcare's Board

Each day at Youngcare is both inspiring and heartbreaking. Inspiring because our supporters are so humble and generous, and because the young Aussies we work for continue to battle with little complaint and a silent voice.

It's for this very reason that the days at Youngcare are heartbreaking too – the lack of care and housing options are so “normal” for so many people that they live without hope, choice or independence...a tragic reality for too many in our beautiful country.

As I took on the role of Chairman of the Board in July this year, I vowed to continue the work of our Founders to fight for those who cannot fight for themselves – young people forced to live in aged care nursing homes.



I know, more than ever before, that we can only do this because of you.

Because of you, we've been able to achieve so much this year for some of the most vulnerable members of our society.

Your support has meant that we've directly assisted hundreds of young Aussies to avoid a lifetime in aged care. Your support has meant that Youngcare has been able to invest in programs and projects that will deliver on our mission and provide financial stability. And most of all, your support has meant that thousands of young Aussies have hope that change is possible, in their lifetime.

On behalf of the Youngcare Board, I would like to sincerely thank you for caring about the issue of young people forced to live in aged care, and for continuing to support the philosophy that aged care is no place for any young person.

The next 12 months will bring even more challenges for Youngcare with new projects and programs, but we know that with your support, we can continue to deliver on our promise that every young Aussie deserves to live a young life.

Thank you.

Nic De Luca
Chairman, Youngcare

A message from Youngcare's CEO

As 2013 comes to an end, we take a moment to review how we've been able to achieve our mission to get young people out of aged care.

With this reflection comes a timely reminder that you are the reason we are succeeding in achieving a better life for young Aussies.

Youngcare was created not by four Founders pushing for choice and dignity for their loved one Shevaune, but by a force greater than this; the combined support of the community and businesses to create meaningful and lasting change for generations of young Aussies trapped in aged care.

It's this movement that you are a part of. Your support means that we are able to continue our battle to help Australians who need it so desperately.

With your support, we're proud to say we've achieved a great deal in the past year. We:

- provided over 110 young people with an At Home Care Grant
- secured funding from the Queensland Government to enter into a partnership with MS Queensland to tackle the elderly carers issue
- expanded the Youngcare Connect hotline nationally
- re-evaluated Youngcare to ensure that our mission is being achieved
- advocated for the introduction of a National Disability Insurance Scheme
- worked to engage the community to raise awareness about issues young people with a disability face.

With the New Year fast approaching, we know that it's you at the centre of our success, and we cannot thank you enough.

Thank you again.

Mark Foley
Chief Executive Officer, Youngcare



Sydney Project

The Youngcare Apartments Sydney Project was launched in November 2012, helping to shine a bright light on the issue of young people living in aged care.

The Sydney Opera House turned red for the evening, and lit up the Sydney skyline to recognise the importance of this new housing project.

Not only is this a momentous project for Youngcare, it also stands as a beacon of hope for the 7,500 young people living in aged care. The Apartments will be a replicable and viable housing model and will be more tangible evidence that change is possible in our lifetime.

The Apartments will be built in Auburn in Sydney's West, and will be home to eight young Aussies.

Youngcare will be delivering a Best Practice Model of Care and Housing for young people with high care needs. As well as having eight self-contained Apartments, the Apartments will also feature an overnight guest room, common areas for social engagement and specialised equipment.

The Development Application for the Apartments was lodged with Auburn City Council in May 2013. A robust community engagement plan has been developed to ensure the local community is informed as the project develops. We anticipate completion towards the end of 2014 at this stage, pending Council approval timeframes. The project was successful in receiving \$1.5 million in capital assistance funding from NSW Government.

Alongside The Haggarty Foundation, we're also proud to have Lend Lease, Griffith University, Channel Nine, GIO, Cox Architects, Herbert Smith Freehills, Aurecon Engineering, Place Design Group, TTM, Butler Partners, Trish Lapsley Access Consultancy, Graham Brooks and Associates, Aecom and McCarthy Consulting Group join us in our endeavours.

We also recognise Morrison Design Partnership Architects, JK Group, Engineering Partners, Blackett Maguire + Goldsmith, Arboreport, JHA Consulting Engineers and Noel Arnold & Associates who are providing assistance.

We look forward to welcoming you through the doors of the Sydney Project later in 2014.



The Sydney Project will be the first Youngcare housing in New South Wales

Elderly Carers Grant Project

Earlier in the year, Youngcare was successful in its bid for a \$1 million capital funding grant under the Queensland Government's Elderly Parent Carer Innovation Trial.

The funding will contribute towards our Albany Creek Apartments which will be undertaken in partnership with MS Queensland.

This new housing project will be the first of its kind, consisting of eight, two bedroom apartments, four of which will be used for young people with high care needs living with elderly parent carers, two of which will be occupied by young people with mid care needs within a small family and two of which will be used to generate rental income as mainstream rental.

The rental income generated will contribute towards maintenance, administration and upkeep of the Apartments. Youngcare will retain ownership of the Apartments. Our target delivery date for the project is mid 2015.

Wooloowin Project

Youngcare has now developed concept architectural plans for a new two-staged development on a block of land that Youngcare successfully secured from the Queensland Government in Wooloowin.

The first stage of this project will comprise a four bedroom share-house, which will look to challenge common issues associated with resident privacy and choice in housemate selection. This type of building is a new innovation from Youngcare – until now all Youngcare Apartments have consisted of seven or more apartments.

The second part of this project will consist of co-located family homes which will offer another option, aiming to keep family units together while providing high care support.

The share house project has received a funding pledge of \$300,000 from Master Builders Association. We are targeting completion of the first stage development for the third quarter of 2014, followed by the second stage in 2015.



The Wooloowin Project will feature a share house and a family home model

At Home Care Grants Update

With the \$1 millionth dollar distributed this financial year, the Youngcare At Home Care Grants have provided essential support to 217 young people with high care needs and their families since being made available in 2009.

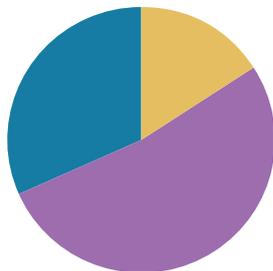
Beginning in Queensland, the grants were also offered in New South Wales in 2011 and Victoria this financial year. The grants provide one-off funding for essential equipment, home modifications and emergency respite support. In 2013, four grant rounds were made available to young people with high care needs and their families.

Two rounds were conducted in Queensland, and one each in New South Wales and Victoria. The ongoing support from Suncorp Insurance in Queensland and GIO in New South Wales has ensured these state based rounds have received the funding to distribute to those who need it most.

Each of these rounds highlighted the immense unmet need in the community for these often basic, yet incredibly vital pieces of equipment, home modifications and emergency respite care.

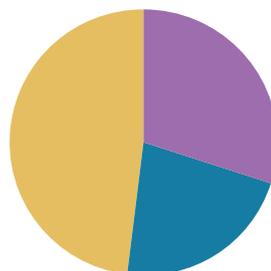
112 young people with high care needs received funding across the four rounds.

Queensland funding allocation
October 2012



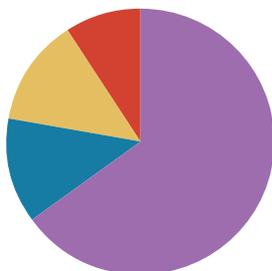
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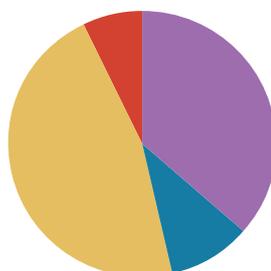
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Youngcare Connect

Youngcare Connect, proudly supported by Suncorp Insurance, is a national service that provides free support and information to young people with high care needs, their families and carers.

For young people, their families and carers, navigating the disability service can be challenging. Youngcare Connect provides a central service, where people speak to a Youngcare Connect Liaison Officer.

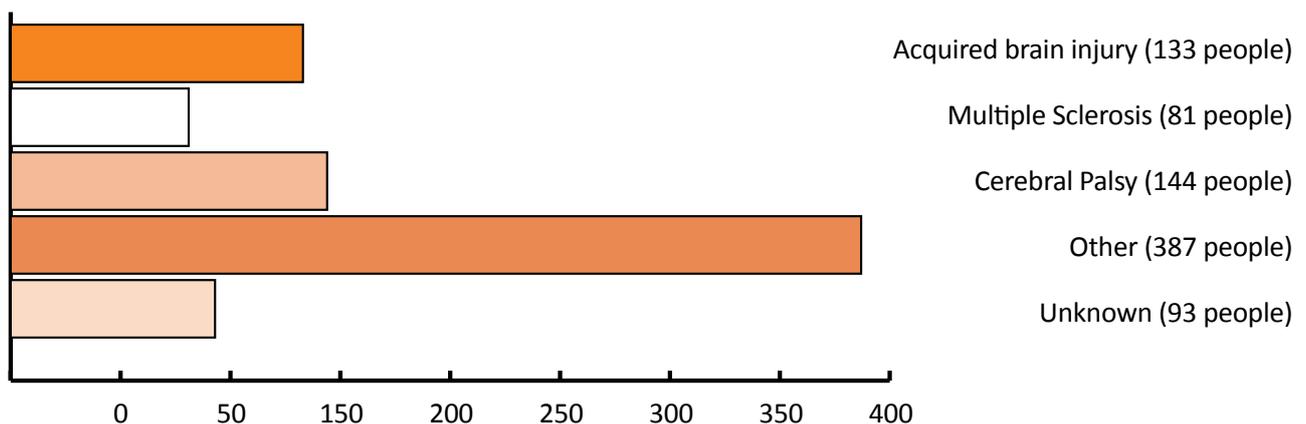
By connecting with Youngcare Connect, young people and their families are given free support and information about a range of options available. These include:

- Accommodation options
- Respite
- Local service providers
- Funding options
- Social and recreational supports
- National Disability Insurance Scheme
- Youngcare At Home Care Grants.

Quick facts

- **To date the service has had 838 new client contacts in 2013**
- **An average of 70 new client contacts per month**
- **An average of 30% of all calls resulted in a referral to relevant state and territory disability services, organisations and community based not for profit organisations**
- **26% of calls were residential requests for Youngcare Apartments, respite and enquiries for other accommodation options**

Types of disabilities



Zaine's story

“My beautiful nephew Zaine was a social butterfly, the life of the party, always surrounded by a million friends. He has the loudest most infectious laugh, cheekiest smile and a massive, loving heart.

At 17 years old, he moved to the big smoke of Brisbane with his best mate and found a job as a Jackaroo in Kingaroy. He was so excited to start work. He brought a car and worked on it with the help of his mate. Like all boys, Zaine loved playing under the bonnet of cars. It was his pride and joy, the first car he had ever brought and he was so proud of his achievement.

Sunday, 13 August 2011 will be the day that changed Zaine's, and our whole family's lives.

Zaine was taking his car for a test drive and had been working on it for weeks, getting it ready for his first day of work which was the very next day. He was driving down a back road when the road went from bitumen to gravel and he lost control. The car rolled and rolled and rolled; Zaine was thrown out of the vehicle landing a distance away from the car when it eventually came to a stop.

Zaine was rushed to the Royal Brisbane & Women's Hospital where he was unconscious and not expected to live. He stayed in ICU on life support for many months, suffering massive head and other significant injuries.

It was touch and go on few occasions with hospital staff preparing our family for the worst. It was the hardest thing in the world to watch a family member lying there and not being able to do anything to “fix” him. Our family struggled to financially support Zaine, but what else can family do? They pull together and get the job done and support each other.

Zaine started healing and growing stronger with his family beside him, talking to him, holding his hand and just being close by. Zaine was eventually moved to the Rehab Unit to start his long, difficult road to recovery.

Zaine is wheelchair dependent. He communicates via an iPad program, he types out his sentences and the machine speaks for him. Zaine has lost the ability to speak. He can make sounds and grunts and groans but the most important words that now come out of my nephew's mouth after three years is “I LOVE YOU.”

Before we could afford to purchase those pieces of equipment, Zaine was unable to communicate. He would just lie there and look at you. You could see he wanted to talk but could only manage loud, almost frightening noises. Not only was it upsetting for us to watch, it was also affecting Zaine. My bright, outgoing nephew was extremely frustrated and depressed, and our spontaneous boy was lost in a body that had failed to heal. He spiralled downhill very quickly with his depression and there was nothing anyone could do. He wanted his life back and he wanted out of the hospital.



Zaine became what they call “maintenance.” He had completed his Rehab and had come as far as he could. The hospital started charging us a “fee” to stay; it was more than what Zaine received on his Disability Support Pension.

Zaine had been on the waiting list for supported accommodation with Disability Queensland for over two years. All Zaine wanted was to move into his own place, his own room with his own things.

After a long three year, uphill battle with constant emails, phone calls, advocacy, social worker support and tears, Zaine was finally approved to move into supported accommodation and into a room to call his own. Beyond excited and happy, I could see my bright, happy boy was coming back.

The only thing that was stopping us from having Zaine move into the house was the financial strain to purchase all his specialised equipment. There is a terrible lack of funding available to young adults to provide much needed medical aids and equipment. We had exhausted all avenues available to us. The last and most important piece of equipment that we couldn't find funding and certainly I could not afford to purchase Zaine's hospital bed. He requires a hi/lo hospital grade bed costing \$2,999 for a basic model.

We contacted every not for profit organisation we could find, but still no luck, until we contacted Youngcare Connect. Because of this phone service, Youngcare were able to facilitate funding so we could purchase the bed we so desperately needed.

Without the support of Youngcare, my beautiful nephew Zaine would have lost his placement and still be in the hospital, back on another waiting list, spiraling back into depression.

All my nephew wanted was to get out of the hospital and start living his life. The future is going to be hard for Zaine but with family support we can achieve everything, and anything is possible for him.

Zaine was able to move into age-appropriate accommodation, and avoid a future in aged care.

The future of the National Disability Insurance Scheme

On Tuesday, 21 March 2013, so many young Aussies with significant and permanent disability, their families and carers had new reason to hope for a brighter future; the National Disability Insurance Scheme (NDIS) became law.

Launch sites began around the country from 1 July 2013, with full implementation anticipated by 2018-19. This reform will revolutionise the nation's entire disability system. For the first time, individuals with permanent and significant disability will receive reasonable and necessary support suited to their individual care and support needs; a complete overhaul of the blanket approach that is currently provided.

Youngcare is proud to have contributed to the development of this ground-breaking policy which will go down in Australia's history as a game changer. In January 2013, Youngcare prepared a submission in response to the National Disability Insurance Scheme Bill 2012. This response was co-authored by two residents currently living in Youngcare Apartments. Our response covered what we recognised as key policy issues within the Bill:

- The concept of "age appropriateness" was not referred to in the Bill.
- When individuals suddenly acquire disability in adulthood (through disease or injury), a special set of circumstances must be considered. For example, many individuals will already have developed their own obligations (to dependents, mortgages etc) that they will need to fulfil. The provisions of the Bill would need to help them do this.
- A lack of appropriate housing stock in 2019 when the Scheme opens Australia-wide is an obvious and predictable area of market failure and needs to be addressed early.

In response to our submission, Youngcare was invited to participate in the NDIS Senate Committee hearing in Canberra in March 2013. Youngcare took the opportunity to elaborate on the key issues raised in our written submission, and answer the Senate Committee's questions on the issues faced by young Aussies with high and complex care needs.

A key focus in Youngcare's interaction with the NDIS Senate Committee, was the lack of funding for capital works to build age appropriate housing, and the fact that questions regarding its resolution continue to go unanswered. Even if every young person in aged care receives their funding on 1 July 2019, with no age appropriate housing, there will be nowhere for them to call home, and they'll remain in aged care. As yet, the State and Federal Government haven't outlined a way to address this issue, so we are continuing to lobby Government for an appropriate solution.



Youngcare resident Bronwyn was one of the co-author's of the National Disability Insurance Scheme submission

To date, Youngcare has engaged extensively with the National Disability Insurance Agency, and with Government at all levels to lift the lid on this otherwise unspoken issue. Youngcare has also undertaken a proactive and coordinated media campaign to raise public awareness of the impending market failure. We know the predicted shortage in housing stock is a problem that cannot be solved alone. It will take the combined efforts of business, community and Government to ensure the issue of young people in aged care can be solved in our lifetime. Into the future, our work in creating a replicable and viable care and housing model for young people with high care needs will remain a key focus.

The National Disability Insurance Scheme is a reform of magnificent scale and Youngcare wholeheartedly supports its implementation.

Researching an age appropriate model of care and housing

Through our research partnership with Griffith University, we are proud to be pioneering a consultative, and evidence based approach to the development of care and housing models for young people with disability. We are currently two years into the three year partnership agreement and to date, two key projects have started to emerge.

- The Youngcare Livewell Model of Care; and
- Evidence Based Design Specifications.

The Youngcare Livewell Model of Care is based on principles of self-determination, meaningful life roles, relationship centred, and individual needs (including human rights and person centred practice). Supported by three assessment tools (self, external and plain English), the Model represents the world's first age appropriate framework for the provision of care, designed specifically for young people with high and complex care needs.

Youngcare's Evidence Based Design specifications developed in partnership with Griffith University will not only inform the disability sector, but also the property development industry (i.e. social housing, commercial development).

The design specifications are based on a combination of best practice already taking place worldwide, and the advice of young people with high care needs. The design specifications will fully enable the delivery of the Livewell Model of Care within a specialist accommodation environment, which promotes a homelike ambience.

Due to be released in 2014, each project will serve to inform the sector, and the public, of best practice in the provision of care and housing for young people with 24/7 care needs. Most importantly, the end product will be shaped by the most important stakeholder; the end user.

A message to you from Todd

I have lived in the Youngcare Apartments since 27 December 2012; it has literally been a life-changing event for my family and I.

Before moving into the Apartments, I was living in my parents' house on the Sunshine Coast. They were my primary carers since birth. I had turned 18 in 2001, and desperately wanted to live in Brisbane so I could have the opportunity of a university education. This opportunity was denied to me because as DSQ said at the time I was not 'disabled enough'. Up until November 2011 we received no funding from the State Government.

The only reason I had the opportunity to receive funding was that I was diagnosed with a depressive illness in addition to my physical diagnosis of Cerebral Palsy. I received in home support of four to six hours a day for one year, but this was designed as a temporary measure. In other words I had to fall off a metaphorical cliff before the government bothered to assist me.

Finally in December 2012, I was so frustrated with the inefficacies, I turned up to the local DSQ office on the last day before the bureaucrats went on Christmas break. I locked myself in, and demanded I be allocated a place to live in Brisbane, so I could complete my PhD in political science. Desperate times called for desperate measures. I was very fortunate to end up at Youngcare.

I took a tour with the Apartments Manager who was very accommodating and assured me that I would not be living in an institutional environment - my family's biggest fear. I was assured that I would gain my much needed autonomy and my parents were satisfied that I would be living in a safe and secure environment. At the end of the tour, we all cried because it was what we always wanted. It is important to acknowledge the role Wesley Mission Brisbane also play. They employ the 31 carers who staff the Apartments. Each of them is outstanding and professional in offering the highest standard of care.

Since I moved into the Apartments, all aspects of my life have become immensely satisfying. My professional career as an academic and freelance writer has improved exponentially, including an opportunity to write for The Conversation, which I would not have had if I still lived on the Sunshine Coast. I also have the opportunity to meet with my PhD supervisors more often, which means I have become more productive in writing my PhD.

Most important of all, I now have the opportunity to participate in the activities I always wanted to. In April this year, I met my favourite band, Tegan and Sara. Even though you probably don't know who they are, be assured it was the highlight of my life. Socially, I am now able to reconnect with my friends, the great majority of whom live in Brisbane. Brisbane is the place I always wanted to live.

On behalf of my parents and my brother, I would like to thank you for helping Youngcare. We cannot explain or quantify how much you have made our lives greater. It took us a while to get here, but we finally got what we wanted.

Todd Winther



Todd has found independence at the Youngcare Apartments

Reaching the policy makers

As the expert on issues faced by young people with 24/7 care needs, Youngcare recognise that Australia's policy makers need our advice and feedback to shape the reforms much needed by the disability sector.

Youngcare places significant emphasis on the importance of Government engagement to ensure young people with disability, their families and carers benefit from effective policy adjustment and implementation.

In 2013, Youngcare pursued extensive engagement with over 40 state and federal parliamentary members across Queensland, New South Wales and Victoria. In addition, Youngcare met with all disability centric politicians in Government at all levels.

Recognising the distinctly siloed approach to the provision of support to people with high and complex care needs, Youngcare has also made special effort to consult and advise representatives in sectors other than disability.

For example, the synergies between Health and Disability prompted Youngcare to connect with Queensland's Minister for Health, and with other representatives in the Health and Ageing spectrum. In an effort to reduce the number of young people transitioning from hospital to aged care after acquiring disability following illness or injury, Youngcare is working closely with Queensland Health to enable alternative pathways better suited to the needs and wants of young people.

We look forward to increasing our engagement in the coming years with Governments at all levels, and on a broad scale, to ensure we get the best outcomes possible for young people with severe and profound disability.



Disability Discrimination Commissioner, Graeme Innes, during his visit to the Youngcare Apartments



A final word

We are grateful for your friendship, dedication and support.

In this Impact Report we would like to pay tribute to the valuable contributions you have made to Youngcare and in particular the young people with high care needs that need our help.

It is through ongoing support and commitment that together, we can achieve our mission of getting young people out of aged care.

A BIG THANK YOU.

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