

identitywa operates ‘Riverton House’ which provides daily or weekly respite for families with children who have a disability. At first, we tried it for a few hours. Eventually Mikayla went for her first overnight stay and Brian, Daniel and I went to the movies, something we loved doing but just never got to do.

We have developed such wonderful relationships with everyone at Riverton House. Mikayla loves going there and I feel the staff love her just as much as we do, if that’s possible. When you arrive, there is always laughter and the smell of home cooked meals, it’s just like home. I often joke with Brian that I’d like to stay there myself some days.

Michelle, Riverton House’s Coordinator, has been there forever, and is always available to help, no matter what! Agata is the person who provides Mikayla’s In Home Respite support and she comes once a week. She and Mikayla have a very unique bond.



I ask what Marina and Brian’s hopes are for their daughter in the long term. “You know Mikayla has been tested for over 2000 known conditions and they still haven’t classified exactly what her condition is. To be perfectly honest, we no longer care. What name they might eventually give to her condition is irrelevant, don’t you think? To us, she’s perfect just the way she is.

Our hopes are just like any parents; that our child will have a happy, healthy and joyous life, and with our help, over time, that she will acquire some skills of independence and have the ability to make choices” Marina said.

“Brian and I are just so grateful and thankful for Mikayla, for Daniel, for our marvellous family and for the unconditional love and support they offer. We realise and appreciate what is most important in life.

It has been and is ‘love’ that makes the difference... actually, ‘love and family’” she adds.



Editor’s Note: BROTHERLY LOVE...

Marina shared with me a beautiful reminiscence about Daniel, Mikayla’s ‘big’ brother. One day, when Daniel was at basketball, Marina and Mikayla were watching from the sidelines when Mikayla started to have one of her screaming outbursts. Worried that Daniel might be embarrassed, Marina wheeled Mikayla to the end of the court away from the game and other parents.

Daniel stopped right in the middle of the game and came running over asking what Mum was doing. When she explained, Daniel said “No way mum, Mikayla is my sister and I love it when she comes to see me play...and she can’t see me from over here” ...and so they went back to the sideline.

Now that is fine example of unconditional love, acceptance and inclusion, for us all. **Good on you Daniel!**

She’s one of the family, in fact, everyone at Riverton House has grown to be a part of our family in a way” said Marina.

“Mikayla is completely dependent on others for all aspects of her daily life, and I know that she is safe and well cared for in the hands of the exceptional and committed staff there.

Mikayla has benefited greatly from “conductive education (CE)” at Carson Street School. CE is a special educational program for children with physical and neurological complications. CE sees the child as a whole, recognising that each area of development impacts on the next. Physical skills, play skills, communication, social interaction, exploration and self care skills are all developed within a fully integrated program, planned and led by specially trained educators.

It is remarkable what a difference Conductive Education has made, absolutely liberating” said Marina.



Pictured: Tim, Marco, Jo Sharland (Social Club Coordinator), Nat (Recreation Assistant), Danielle, Kyle, Nick, Andrew, and Lauren (Volunteer)

We meet Nick at Cottesloe Beach on a beautiful Saturday morning. He’s waiting to meet friends from the Social Club he belongs to; today, they’ve arranged a special guided tour of the amazing “Sculptures by the Sea” exhibits.

The Social Club is open to Members only; as they begin arriving one by one, I notice that they all have one thing in common – they love to have fun and really enjoy seeing each other and getting together...

...oh, and we should mention that every member also has a mild intellectual disability.

Nick (29) lives at home with his parents Ann and Terry although many members live independently. Some members have their drivers licence and many have jobs – in Nick’s case, he works at a school canteen during the week.

Nick has a fantastic, infectious laugh and a cheeky sort of a grin, but in a good way. He’s been a member of the **identitywa Social Club** for a few years now. The members get together every four months and discuss what activities they would like to do for the next few months. These activities are then scheduled fortnightly on the weekends for a few hours. Last year, many of the group went on a holiday to Bali for ten days.

Jo Sharland, Coordinator of the Social Club explains: “the purpose of the club is to help foster friendships, to develop social skills, to overcome any feelings of social isolation they may feel and above all else, to have fun.

Our job is to help coordinate and facilitate the activities the members themselves choose. On the day of the planned activity, Nat (Recreation Assistant) and at least one volunteer like Lauren, will be there to help in whatever way possible and to make sure everyone stays safe” she said.

I ask Nick what he likes about the Social Club, he said: “Definitely the good friends I have made, we all have fun together. I really look forward to it”.



While we take a few quick photos, Nick laughs and jokes constantly. Before he leaves to join the rest of the group for the art tour, I ask if I can join them.

He says **“Sorry... Members Only”** and quickly walks away chuckling to himself.

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LOVE & FAMILY:

Mikayla’s Story



Mikayla (6) is a beautiful little girl, with a smile that makes you immediately smile too.

She loves having her photo taken and is very excited because Mum (Marina) picked her up early from school today to meet us. It could also be because tonight is her Nonna’s 75th birthday celebration and Mikayla absolutely loves a family party.

Marina explains: “I have four brothers and one sister and between us (and our partners) we have twenty children. They all simply adore Mikayla, so when the family gets together, which is often as we are all very close, she is almost ‘consumed’ with hugs and kisses from aunts, uncles, cousins and her nonna”.

There is no question that Mikayla is a remarkable young girl. Every day, she faces challenges and has endured more in her short life than most of us can possibly imagine.

“ Mikayla was 3 months old when we first noticed something wasn’t as it should be. Mikayla’s development had stalled, she was irritable, wouldn’t sleep, stopped eating well and had jerky body movements. I took Mikayla to our family’s GP and was told everything was perfectly fine – they told me to relax. I went to another doctor and was told the problem was “an over-anxious mum”.

But I knew, as any mother instinctively does, that my child needed help, so I politely requested a referral to a specialist. After a battery of tests and two days of observation, I can still remember the moment my husband Brian and I were told by the paediatrician that Mikayla had some form of neurological condition, resulting in developmental regression and uncontrollable movements.

From 6 months to 3 years of age, Mikayla had seizures every single day of her life. A good day would mean about 15 to 30 seizures; a bad day would mean over 100.

Every few months we’d make an emergency dash to Princess Margaret Hospital with Mikayla in a ‘seizure crisis’ where she would be stuck in a cycle of seizures that would last for days at a time. As a result of being constantly under attack from these

seizures, Mikayla lost all muscle tone and resembled a rag doll – completely floppy. She lost her sight and hearing (since recovered), and her swallowing reflex which meant she couldn’t take food or water. She lost tactile sensation so couldn’t feel when someone or something was touching her. She would scream uncontrollably for hour after hour, making sleep and family outings very difficult.

Mikayla couldn’t possibly comprehend what was happening to her or communicate her feelings and needs to us. As a mother, I felt tremendous guilt that I was not able to give more of my time and focus to my beautiful boy Daniel (7) who was just a toddler himself at the time. Thankfully, Brian was there and the two of them are very close. There were relationship challenges my husband and I faced, as any couple would. All in all, it was an emotionally draining time.

I first heard about **identitywa** from another mum when Mikayla was about 18 months old. A wonderful lady would come to our home once a week to offer a few hours respite. It allowed me to do shopping, spend special time with Daniel or simply have a coffee and a chat with girlfriends. It was a much needed break from the workload and stress.

Editor’s Note: INCLUSION AND ACCEPTANCE...

I have had an amazing few weeks meeting the families, marvellous staff and some of the many service recipients of **identitywa**. At times it was confronting, sad, confusing, absolutely joyous, educational and overall, a wonderful experience. My hope, their hope, is that we as a community are motivated to help in whatever way we can. But that we do so because they are **people just like us who deserve and need our help... not “disabled” people in need.**

Brett Mendez, Manager, LifeLink



Pictured: Nic, Jessica & Kerry

We are warmly welcomed to Jessica's place on a sunny Saturday morning, a home she happily shares with three house mates around the same age.

The house, opposite a beautiful park in a quiet suburban street, is modern and well maintained. On entering, there is a genuine warmth, an inviting ambience – photographs of housemates and loved ones on the walls, someone watching television in the front room and the smell of coffee brewing in the kitchen.

Jessica, sitting in a comfy lounge chair opposite the kitchen, gives us a huge smile. Her parents, Kerry and Nic, are visiting her today and we introduce ourselves. We settle down for a coffee and a chat.

Nothing remarkable in this so far?

What makes this story special is that Jessica has a disability, and so do her housemates. They require 24 hour, 7 day a week assistance with [all aspects of their lives](#) from professional support workers.

Jessica's is one of twenty-six **identitywa** accommodation properties located in and around the Perth metro area. What is apparent from the first moment you enter is that these are not merely houses, they are indeed "homes".

Jessica's (24) disability has been with her since birth, a result of CMV or Cytomegalovirus – never heard of it, nor had we! CMV is a common viral infection; in Australia, about 50 per cent of young adults have been infected at some stage. In healthy people, it causes a mild flu-like illness which passes harmlessly in a few days. For pregnant women, the infection is highly dangerous.



"I had a normal pregnancy (Jess is our second child) and everything right up to the moment Jessica came into the world was as expected. We had absolutely no warning or inkling that anything was wrong, until Nic and I saw the looks on the faces of the doctors and nurses immediately after they delivered our daughter.

We were eventually informed Jessica had CMV. This resulted in stunted brain development, hemiplegia (partial paralysis of the left hand and leg) and profound deafness. She couldn't speak but thankfully her eyesight was unaffected." said Kerry.

"The worst part was that the virus kept attacking for the next five years, which resulted in severe epilepsy and other conditions. While the virus was active in Jessica for the five years, we were unable to access any type of support or respite. Jessica also had difficulty eating and sleeping.

She would scream for hours on end (part of the condition). Those early years were isolating and difficult. Our world revolved around hospital appointments, multiple surgeries to help straighten hands and feet, physical and occupational therapy." said Nic.

Whilst it must have been one of the most difficult decisions to make, Nic and Kerry knew that for Jessica's long-term well-being and for the sake of all the family, alternative and permanent care and accommodation was required.

"But there simply wasn't this type of accommodation available for younger people at that time" said Nic.

"**identitywa** had for many years been providing us with much needed respite care and been of great help to our family, they knew of our long-term hopes for Jessica. One day they called to advise that **identitywa** was establishing its first group home for younger people with a disability and offered Jessica a place. We did a lot of checking and the organisation made sure all service recipients were carefully matched in ages, needs and conditions.

Jessica moved into her first home at age 13 and so she has been a part of the **identitywa** family for nearly 12 years. It has been marvellous for her. She has continued to develop (limited) communication skills, her health is fantastic, her social skills have expanded and today, she can drink from her cup and help wash it up.

We know that Jessica is very happy here. We know she is well cared for and loved by all the staff. What more could we as parents hope for our daughter, or ask for our daughter." said Nic.



More Than a House, It's A HOME!

Riverton House provides overnight and day respite for more than 70 families who have children from birth to 18 years of age with a disability.

identitywa's Community Services Manager, Ms Lisa Dobrin, said: "Riverton House has the capacity to welcome a maximum of 6 children at a time, and it is full to absolute capacity - 365 days a year!

Whether it's for 3 hours while parents take time-out for themselves, or a week or more whilst a family takes a much needed holiday, Riverton House is a vital asset for families that have children with disability".

identitywa employs 17 permanent and 8 casual staff working three shifts a day (24 hours total) to ensure the highest level of care and support for the children. "We carefully consider the needs of each child; some have a high level of medical needs whilst others have multiple disabilities requiring a greater level of support. It is also important that children of similar ages and needs are welcomed at the same time so they feel "at home" in "our home" said Lisa.

"Established in 1990, it now costs more than \$1 million a year to operate Riverton House. Approx 85% of this funding is generously provided by the Disability Services Commission and the property is provided by the Department of Housing, whose support we greatly appreciate" said Lisa.

I asked Lisa that if she had a magic wand, what would she wish for Riverton House?

"After 21 years of service, a modern spacious house with more single rooms (currently only one), a home with wider corridors and larger bathrooms providing better access. We also desperately need lifting tracks and hoists fitted; it can be real a struggle to lift some of the larger children into bed, the shower or to assist them with their personal needs.

I know Michelle (House Coordinator) would wish for a dedicated Sensory Room designed to help stimulate the children, which greatly enhances their skills development and capabilities" she said.

Editor's Comment: Michelle Logan, Riverton House's much loved and long-serving coordinator and her team, make Riverton House a very special place indeed. They have such wonderful relationships with the families, and especially the children. Everyone at Riverton House is so professional, and you can't help but see that everyone truly loves what they do, and that they care deeply for the children.



Shane Mauger, CEO, **identitywa**

"**identitywa** believes that every person is created equally, and so has dignity and worth. As a result, we believe we are charged with the responsibility, both morally and through the teachings of the Church, to create options for those who are marginalised or devalued. Our vision is to build a compassionate and socially just society, one inclusive of people with disabilities and their families.

“The name **identitywa** reflects the two key focuses of the organisation. The 'id' is a reference to our support of people with an intellectual disability. The 'entity' is a reminder of the spirituality that resides in all people and that we all have unique gifts that we bring to the community and society. Bringing these two areas together is a reflection of what we do - an agency providing much needed care, support and professional services for people with intellectual (and other) disabilities and their families here in Perth, while also allowing for their expressed spiritual needs" said Shane Mauger, CEO, **identitywa**.

It is also essential that we strive to provide opportunities for people with intellectual disabilities to participate and develop skills, so that they may attain value and acceptance within the community and within the activities of the Church." he said.

"I'm proud to be a part of such a wonderful organisation and to work with people who are passionate about the work that they perform. The quality of the supports provided by **identitywa** is a reflection of the values and commitment of the staff engaged to work directly with people with disabilities and their families. Our staff, managers and dedicated Board Members do their utmost to help people with disabilities live a full and rewarding life, and encourage their families to share in the joy they experience as a result.

I want to especially thank Archbishop Hickey for his enduring commitment to help us achieve our mission. I also want to thank all the parish priests, parishioners, schools and generous contributors for your support of LifeLink, through which **identitywa** receives much needed funding.

YOU are all very much a part of our organisation in helping us to build a better society, one which fully embraces and demands the holistic inclusion of people with disability." said Mr Mauger.



Serving the community for **more than 30 years**, this year, **identitywa** will reach-out to help accommodate **108 people with disability**, and support **600 families and individuals** delivering **\$18.9 million** of care.

identitywa provides residential **houses and support for 108 individuals** with disability in community based group homes. Supported accommodation enables people unable to live independently, with the additional assistance and support they require to maintain a high quality of life in the community. Qualified and experienced staff help service recipients develop independence skills, participate in community and social activities, attend work or day activities, maintain their homes and develop friendships.

One-to-one **support for more than 600 families** with a child or adult with a disability living at home with their family. In Home respite provides families and carers with an opportunity to establish personal time for themselves knowing that their son or daughter is being positively engaged and supported in a familiar environment – their family home. Recreational respite also provides the family or carer with the same opportunities as in-home support while their child with a disability participates in fun, community activities of their choosing.

Residential **respite for over 200 families each year** in three metropolitan based respite homes. Respite provides families and carers with an opportunity to briefly step away from their caring roles either overnight or for a few days, allowing both the carer and the person with a disability time away from each other to allow them both the opportunity to grow and have different individual life experiences.

identitywa provide **approximately 400 qualified, experienced and passionate staff** to help assist and support people with disabilities; including qualified and experienced Social Trainers, Residential Aides, Sleep Shifts and Night Awake staff.

Editor's Note: **THE NEED IS GREAT BUT ACCESSING RESOURCES IS DIFFICULT...**
During 2010/2011, 984 people applied for accommodation and community support funding but only 408 receiving funding. The 576 unsuccessful applicants, and thousands more who have not applied, continue to access the limited number of services provided by funded organisations, including **identitywa**. Each year the number of people requiring support increases but with no additional resources:- **identitywa** is required to do more with less.



In 1977, a group of loving parents and supporters shared a vision about the standard of care they wanted and needed for their children with disability. Together, they established an organisation - Catholic Care for Intellectually Handicapped Persons - more commonly known as Catholic Care.

In 1981, the organisation progressed from being a "self-help group" to a fully supported social service agency of the Church. In 2001, following a period of further growth in the accommodation and community services programs the organisation changed its name to **identitywa**.