

Youth with Disability Forum

REPORT



Midlas
Youth with Disability Forum
Thursday, 6th April 2017
5:30pm to 7:30pm

Forum Report



Midlas acknowledges that we are working in Whadjuk country and pays respect to
Elders and all Noongar people, past and present

Acknowledgements

Midlas acknowledges with thanks the broad support received to hold this inaugural forum and the hard work of all involved.

A National Youth Week grant from the Department of Local Government and Communities contributed towards the cost of organising the forum. The City of Swan supported the forum through transport services, catering and a grant to write up the forum report. Brad Lukosius from the City of Swan kindly donated his time to transport attendees and Rebecca Pudney, also from the City of Swan, assisted in the planning and promotion of the event. Photographic services were generously provided on a volunteer basis by Paige King (P King Photos).

Midlas wishes to thank all members of the planning committee. Special thanks to Rebecca Dewar, who co-facilitated the evening beautifully; and Grace Mills, who helped plan the forum and inspired us with her own journey of self-advocacy.

Midlas appreciates the support of Karl Schunker, Paige King and Ellie Yang for volunteering their time on the night of the event. Midlas staff, Megan Butt and Anastasia Causton, worked hard to ensure the forum was well organised and marketed. Thank you to all the organisations that assisted to promote this event.

Midlas' acknowledges funding through the Australian Government Department of Social Services which enables us to provide disability advocacy services.

Lastly, we would like to thank all the young people and parents who so actively participated in the event.



Photo 1: Forum staff and volunteers - P King Photos

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Introduction

Midland Information Debt and Legal Advocacy Service Inc (Midlas) is a not for profit community agency based in Midland that provides financial counselling, tenancy advocacy, disability advocacy and legal service to people throughout the north east region of Perth. Midlas disability advocates offer individual advocacy, guidance and support to people with a disability, their carers and families.

In 2017, Midlas applied for and received a grant from the Minister for Local Government; Community Services; Seniors and Volunteering; Youth to hold a forum for youth with disability to discuss and collaborate on the big issues they are experiencing.

The City of Swan supported the forum through transport services, catering and a grant to write up forum outcomes.

The forum was held during National Youth Week with the aim to discuss current issues or concerns for youth with disability. The forum was also an opportunity for young people to share their thoughts on how services and organisations can engage youth with disability and to support self-advocacy.

Seventeen people attended, including 10 young people, six parents/carers and one service provider.

The forum was co-facilitated by Rebecca Dewar, a young woman who identifies as having a disability, and Christina Kadmos. Five Midlas volunteers assisted with the small group facilitation.



Photo 2: Rebecca Dewar welcoming people to the forum - P King Photos

How the forum was organised

A forum planning committee was established that included Midlas staff and volunteers and two young people with a disability - the co-facilitator and a representative from the Youth Disability Advocacy Network (YDAN). The committee determined the program and key questions for the evening.

The forum was based on a 'world cafe' format, whereby a series of rounds allowed participants to move between tables, each with a specific topic of conversation. The topics for discussion were:

- Relationships with families, friends and others.
- Promoting independence.
- Life after school/university.
- What cheeses me off.
- Services supporting youth with disability.

The latter group topic was designed specifically for parents, carers and service providers attending the forum. Parents/carers could attend any of the round discussions as a support person to a young person, if requested by the young person.

A photographer volunteered their services on the night, with participant consent sought for all images used.

Promotion

Emails and phone calls about the forum were made to 24 schools in the region and over 120 agencies and community groups. Invitations were given to Midlas clients who were young people with a disability.

The promotion of the event focused on targeting youth with disability as the main attendees. Although parents/carers and service providers were encouraged to attend, the focus was on bringing youth with disability together to hear their voice and not the voice of parents/service providers.

Media promotion included Facebook and other social media sites. Local newspapers, The Echo and Community Newspaper Group promoted the event.

Home / General News / A forum to inspire youth with disability



Anastasia Causton and Midlas disability advocate Megan Butt will welcome attendees.

A forum to inspire youth with disability

Posted by: Michelle Beaven | In General News | 22 days ago | 0 | 156 Views

A FORUM to discuss and collaborate on how to better engage youth with disability to lead a better life will be held in Midland next week and the free event is open to everyone.

The Midland Information Debt and Legal Advocacy Service (Midlas) will run the inaugural youth with a disability forum at the Midland Town Hall on Thursday, April 6 from 5.30 to 7.30pm.

Midlas general manager Justine Clarke said the forum was funded by a grant to focus on bringing youth together to discuss and collaborate on the big issues they are experiencing.

The forum will also be an opportunity for them to share their thoughts on how services and organisations can engage youth with disability and to help them empower them through self-advocacy.

Photo 3: Copy of article from the Echo News

Midlas to host free forum for youth with disabilities during Youth Week

March 29th, 2017, 04:00PM | Written by Sarah Brookes | The Advocate NEWS



Justine Clarke and Bec Dewar. Picture: David Baylis

Photo 4: Copy of article from the Community Newspaper Group

Reflections on self-advocacy

Grace Mills, co-founder of YDAN, spoke to the group about her own journey towards self-advocacy.

Grace shared personal reflections on the need to develop confidence in expressing one's opinions and encouraged young people to think about what they really wanted and express this.

Grace's suggested some important things for all young people to remember:

- If you don't speak up that you are unhappy with something or wish to change, then it will not change - only you know what you want, others will not be able to help you if you don't express your opinion.
- Don't be discouraged by someone telling you that you are "wrong". What you may feel is right for you may not fit with someone else but that does not mean you should follow their opinion just to keep the peace.
- The key is to find a group of people with similar thoughts or opinions, so you can build on those ideas and get support.



Photo 5: Grace Mills speaking at the forum - P King Photos

What youth with disability had to say

Each of the cafe tables had a small group facilitator who encouraged discussion and took notes of what young people had to say. Topic areas included questions to prompt and guide discussion, but these were not prescriptive.

Four rounds of discussion allowed young people to move between topic areas or stay within a topic area. The group discussing services supporting youth with disability was only made up of parents, carers or service providers.

The following pages provides a summary of the main issues raised in each of the five topic areas.



Photo 6: Rebecca and Grace addressing the forum - P King Photos



Photo 7: Discussion groups in the room - P King Photos

Relationships

The topic of relationships was broad to include families, friends and romantic relationships. Guiding questions were:

- *What is important for you about the different relationships in your life e.g. family, friends, boy/girl friends?*
- *What are the challenges for you in different relationships? e.g. making my own choices, relationship skills, opportunities to socialise etc.*



Photo 8: Relationships small group discussion - P King Photos

Family

'Living with people who treat me well, is very important'.

For many participants, family helps them feel loved and appreciated and a number said that their mother or father were someone they can always rely on. Many said that they feel family is a good support system and they felt encouraged by their family to pursue opportunities.

Some young people said they did not feel comfortable living with family because they made them feel down. Others spoke of feeling criticised, disrespected and experiences of domestic violence.

A couple of young people felt the court system of awarding custody to the mother and excluding the father can cause problems - the feelings of the child/ children should be considered.

Many expressed the view that families can be hard and challenging at times - there can be arguments with siblings or parents. Sometimes parents can be too controlling, making it harder for young people to make their own choices.

Friends

'It is often easier to talk to friends about how I feel than family'.

'I have moved schools a lot and it is difficult to form friendships and retain the connections'.

'If you have been bullied in the past, it would make you nervous about talking to new people because you are always going to have that in the back of your head'.

'Friends make me feel comfortable to chat about anything'.

Friends are important and can be easier than family. Friends are often more likely to hear about the negative feelings because they can be trusted to understand.

Going through similar experiences, issues, opinions and values are important in choosing friends, as is feeling someone is trustworthy and not aggressive.

It can be hard to maintain friendships - change of address, moving to different schools and life changes were major factors in whether friendships would last. Some spoke about wanting to have more friends than they do and about being bullied in school due to their disability. Many agreed that bullying is a real concern.

Assumptions about disability can be a barrier to forming relationships with people - sometimes people assume that someone with a disability is mentally unstable.

A number of young people agreed that there can be a difference between interacting with someone with a disability and someone without a disability. People without a disability can 'feel awkward around us'. Some felt people with a disability were more likely to understand if they needed assistance, would ask questions and be willing to help without being asked.

Romantic relationships

Some participants said that they would like a romantic partner, others were unsure and some said that they might like a romantic relationship but they had not yet met anyone who made them want to develop those feelings. One person shared that they had considered a romantic relationship but had been shut down by the other person.

Many agreed that it was important to find the right person and that they were looking for certain qualities in any person they would want to form a relationship with, such as:

- To value me for who I am.
- I don't want someone who is controlling.
- I don't want someone who moves too fast.
- Trust and having some similar interests.
- It is important for the person to understand my disability.
- Loyalty is important as I do not want to be cheated on and feel betrayed.

Independence

The topic of independence explored what it is like for youth with a disability to achieve increased independence in their lives. Guiding questions were:

- *What makes you feel independent?*
- *What stops you from feeling independent?*
- *What community factors hinder independence e.g. transport, community attitudes.*



Photo 9: Promoting independence small group - P King Photos

What makes you feel independent?

'Understanding myself and my feelings is important. Accepting myself'.

Young people spoke about being able to take care of themselves - physically, mentally, emotionally.

Getting a job and increasing financial independence was an aspiration of many of the young people. A number of them spoke about wanting to rely less on their parents.

There are practical life skills that many spoke about wanting to develop:

- Being able to organise and get to appointments.
- Managing prescriptions.
- Social skills and knowing what to say in public places.
- Living on my own - cooking, cleaning, washing for myself.

Setting and achieving a goal was seen to be an important part of independence.

Using public transport, access to transport and being able to get to where young people want to go was also seen as very important. Some spoke about their desire to get a driver's license.

Other things that young people noted helped independence was having their own phone and looking after pets.

Barriers to independence

'People constantly doubting me leads me to doubt myself at times'.

There was strong agreement that transport was a really big barrier and many spoke about their frustrations with the Taxi User Subsidy Scheme.

Accessibility was another barrier - this includes buildings, information, entertainment and all sorts of things.

Some young people spoke about not wanting to let people down or upset them, which can mean not being assertive about what they really want.

A number of young people said that making decisions independently of family can be hard when there is pressure from family. Family expectations and restrictions can be a barrier.

Lack of phone and not having a driver's licence can be a barrier.

Life after school or study

The topic of life after school or study explored young people's concerns and hopes as they transition from one stage of their life to another. Guiding questions were:

- *What are your dreams and options for after high school/university or whatever space you are in now?*
- *What is hard about times of change and transition in our lives?*
- *What are your concerns for the future?*



Photo 10: Life after school or study small group

Key themes

Young people shared aspirations of wanting to work, make money, travel and maybe move out of home one day.

People spoke about a desire to be as independent and self-supporting as possible.

Many young people said that they were or have been worried about what to do after school.

In thinking about future transitions, many felt fear of the unknown, being judged and not having the support needed in the future.

A very big concern is about getting work and keeping work. Some said that they felt despondent about real employment choices, with a proper wage.

There was general agreement that a supportive network is really important at times of change.

Some people spoke about their concerns for the future in terms of climate change, the economy and house prices.

Things that are hard about change include:

- Fear of failing and letting people down
- Accepting and adjusting to the changes
- Changes to routines
- Sleep changes
- Change can be stressful and worrying
- Feeling safe.

What cheeses me off

This topic area was designed to allow young people to talk broadly about things in life that annoy them - in any area of their lives. Guiding questions were:

- *What annoys you most as you get older and seek independence?*
- *Which of these things are related to having a disability and which ones are about life in general?*

Key themes

Trying to study and learn new things can be really hard.

Work experience - wanting paid not unpaid employment.

Not being able to choose my own carers.

How to address co-workers when I am not getting on well with them.

Lack of options and freedom.

Lack of motivation due to limited life choices.

Parents making decisions for me and not knowing or asking what I want.

Trouble knowing what options and services are available to me.

People making assumptions about me when my disability is not visible.

Labels and discrimination - for example using my disability as an insult.

Underestimating me and presuming my capabilities.

Funding decisions by people/service providers who are disconnected - imposed from above, instead of asking 'what is best for you?'

Parents criticising the way I look and what I wear.

Being undervalued at work and not trained properly.

Fear of recrimination when exercising my rights.

Transport and the Taxi Users Subsidy Scheme.

Frustrations with politicians promising to do something and they don't.

Services supporting youth with disability

A discussion group for parents, carers and service providers looked at the topic of services that support youth with disabilities. Guiding questions were:

- *In what ways can service organisations both help and hinder youth with disability achieve their goals?*
- *How organisations can better engage with youth with disability?*



Photo 11: Services supporting youth with disability discussion group

Key themes

'Services need to better meet expectations - many services have become about business, not people'.

A common theme was that services make many promises but do not always deliver - and that they should do what they say they are going to do.

Parents and carers spoke about ending up having to do a lot of the work themselves and having to continually follow up with service providers. A number of people said there was too much requirement for self-management and not enough choice.

There were many concerns about National Disability Insurance Scheme (NDIS) - lack of accountability, flexibility and choice. People's experiences have been that only a minimum level of services are funded. There is a need for more accountability and clear reporting in services provided.

Some suggested that there are too many organisations providing services and too much competition, without enough coordination. People spoke about the difficulty in having to constantly repeat their story.

The quality of staffing and services was a concern of many:

- Workers focus on setting goals but then there is not enough follow through to help young people achieve their goals.
- Staff are not always qualified and often lack experience and skills for communicating with young people with disability.
- Lack of understanding and follow-up.
- Lack of engagement with the young person.
- Lack of continuity with staff - often lots of changes. Dealing with change can be hard for youth with disability.
- Assessments are often a tick the box process - not a real focus on the young person and family.

A key theme was that it is very difficult for youth with disability to find employment - more support is needed in this area. There is not enough assistance with transition to work.

People agreed that there was a general gap in appropriate services for the years 15 to 25, including vocational and social services. More informal supports for this age group are needed.

Evaluation

All young people attending received an on-line evaluation form for their feedback. Only three responses were received. Of these, two thought the forum was 'brilliant' and one said it was 'really good'.

'The world café was a surprise, I thought I would be listening to a lecture, but it worked so well.'

People especially liked the young person who facilitated and led the forum - 'she was fabulous'. There were no suggestions made on how the forum could have been better.

Of the three responses, one had heard of the forum from a Midlas staff member, one from the facilitator and one had heard of the forum from a City of Swan newsletter.

Reflections

During promotion of the Forum great interest was shown by disability service providers and government departments in attending the event. This posed a concern to Midlas being the organisers of the event, as the purpose of the forum was to promote local youth with disability and their voice. We felt that if service organisations attended it was likely that the forum's main focus would be altered to highlight the providers' opinion and not that of youth with disability. Within the planning committee it was discussed that it may be overwhelming to have a larger proportion of service providers attending as this may discourage open communication. To counter this, the event promoters contacted the registered providers to enquire whether they were going to be bringing youth with disability to the event and most providers de-registered. All interested providers will receive a copy of the formal report.

Promoting the attendance of youth with disability aged between 15-25 years of age also had its challenges that included:

- Providing a venue that was close and safely accessible to public transport due to the time of event (5.30pm to 7.30pm).
- That the event was planned in the last week of the school term.
- Parents determining that their child or children with disability would not find any benefit in attending or due to their disability e.g. non-verbal, would not be able to contribute.
- Ensuring the forum was balanced between information that was provided and giving youth with disability enough time to feel comfortable to discuss the 5 topics.
- Who and how to market the forum to get participants to attend.
- Lower than expected participant numbers.

Although the numbers for the Forum were small – the discussions that came from the attendees provided extensive feedback about the 5 topics that were discussed. The Forum suited a smaller/informal approach which made the attendees feel at ease and

many of the attendees indicated that this was their first time attending an event of this nature.

Outcomes

This Forum's objectives were not quantifiably measured however we believe that the outcomes for participants included:

- It allowed parents and providers to have a better understanding of some of the issues that are facing youth with disability.
- Gave youth with disability the opportunity to attend a forum that focused on them and provided openings to meet other like-minded individuals
- Provided Information about how youth with disability can be involved in activities including advocacy opportunities, for example through YDAN
- Provided youth with disability the opportunity to voice their issues and concerns in a safe environment.

Going forward

The forum report will be provided to everyone that attended the forum and made available broadly to local service providers and members of the public. Although the attendance numbers were small, the key messages and themes were heard loud and clear. Youth with disability want to be included and consulted in decisions that impact them – these are not only bureaucratic/legislative decisions but also day-to-day matters relating to individual choices, living in the community and getting treated fairly and equitably. The forum has highlighted that youth with disability do want to be involved and can have a voice – people just need to ask.

Midlas will use the feedback received to ensure that their services best meet the needs of youth with disability and will promote this information to all other stakeholders that they engage with. The forum will also be used as a springboard for further engagement with youth with disability.



Photo 12: Picture of Sticky Wall with 5 topics for discussion

Appendix 1: Background on youth with disability

Australian Bureau of Statistics (ABS) estimates that about 1 in 13 (8%) young people aged 15 to 24 years has a disability. According to the ABS¹, in 2012:

In the 15 to 24 years age bracket

- 17% reported that they received assistance, and felt their need for assistance was met; 7% reported that they received assistance but required more; and 3% reported that they needed assistance, but did not get it.
- Around one-quarter (24%) of young people with disability accessed disability support services - one-half of these young people accessed disability employment services (50%), and just over one-third (37%) accessed community support services.

In the under 18 years age bracket

- Most (86%) children and young people with disability attended mainstream schools, while the remainder attended schools specially designed to cater for the needs of students with disability.
- A higher proportion of children and young people with disability lived in single parent families (34%) compared with children who had no disability (18%).
- Almost one in two children and young people experienced learning difficulties at school (43%) while more than a third (35%) had trouble fitting in socially. There was no significant difference between children in special or mainstream schools when it came to experiencing learning difficulties or fitting in socially.

Evidence shows that young people with disability have decreased opportunities to participate in education, employment, social and community opportunities. Some young people with disability experience particular vulnerability - rates of abuse and neglect are higher, there is a higher chance of requiring child protection services and those with acquired brain injuries, cognitive impairments and learning disabilities are over-represented in the criminal justice system.² There is also evidence that young people with a disability are more likely to experience mental health problems.³

¹ Australian Bureau of Statistics, 4430.0 - *Disability, Ageing and Carers, Australia: Summary of Findings*, 2013, <http://www.abs.gov.au/ausstats/abs@.nsf/lookup> and 4427.0 - *Young People with Disability*, 2012, www.abs.gov.au/ausstats/abs@.nsf/Lookup/4427.0main+features52012.

² Australian Institute of Health and Wellbeing, 2015, *Young People (15-24)*, <http://www.aihw.gov.au/australias-welfare/2015/young-people/#t9>

³ Western Australian Commissioner for Children and Young People, February 2013, *Policy Brief - Children and Young people with a Disability*, <https://www.ccyp.wa.gov.au/media/1290/policy-brief-children-and-young-people-with-disability-february-2013.pdf>.

The Australian Clearinghouse for Youth Studies found that issues relating to youth and their experience of disability are rarely highlighted by the media or within the political sphere, and that young people with disability are often considered primarily in reference to their disability, rather than as developing young adults⁴.

In 2013, the Western Australian Commissioner for Children and Young People collected the views of 233 children and young people with disability. The key issues talked about were love and support from families; enjoying the company of friends; wanting to be involved and included; wanting to participate in activities; being connected to the community; and a desire to be independent. According to the Commissioner⁵:

'In many ways, they have the same views as the majority of children and young people in Western Australia. They also have a disability. In some cases, this affects their communication, coordination, senses, thinking processes or mobility. But as they told me, their disability is just one part of their life – they want to be known for who they are, as a person with abilities, talent and potential'.

At the time of the 2011 Census, there were 440 young people aged between 15 to 24 years that required 'core activity assistance' residing in the Midlas disability program areas of Swan (C), Bassendean (T), Kalamunda (S) and Mundaring (S). Table 1 provides a breakdown for each local government area of young people who required core activity assistance, by age by sex.

⁴ March, N., 2012, *Youth Disability in Australia, Face the Facts Briefing*, Australian Clearinghouse for Youth Studies, www.acys.info/facts.

⁵ Western Australian Commissioner for Children and Young People, November 2013, *Speaking Out About Disability* <https://www.ccyp.wa.gov.au/media/1420/report-disability-speaking-out-about-disability-november-2013.pdf>

Table 1: 2011 Australian Census, Core Activity Need for Assistance by Age by Sex (LGA)

		Swan (C)		Bassendean (T)		Kalamunda (S)		Mundaring (S)		Western Australia	
Sex	Age	Total	Has need for assistance	Total	Has need for assistance	Total	Has need for assistance	Total	Has need for assistance	Total	Has need for assistance
Persons	All ages	108,460	3,772	14,404	652	53,568	1,708	36,532	1,165	2,239,171	79,072
	15 - 19	8,133	144	845	5	4,004	58	2,783	48	148,207	2,240
	20 - 24	7,403	94	972	19	3,378	32	2,176	40	159,011	1,725
Males	All ages	54,018	1,848	7,174	296	26,534	773	18,767	548	1,126,178	36,132
	15 - 19	4,183	90	448	-	2,049	29	1,463	36	76,469	1,419
	20 - 24	3,759	58	540	12	1,707	23	1,281	21	82,189	1,032
Females	All ages	54,442	1,924	7,230	356	27,034	935	17,765	617	1,112,993	42,940
	15 - 19	3,950	54	397	5	1,955	29	1,320	12	71,738	821
	20 - 24	3,644	36	432	7	1,671	9	895	19	76,822	693

Data extracted from ABS.Stat © Commonwealth of Australia.



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