

Submission S023

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Family and Community Development Committee



Submission

Inquiry into Services for People with Autism Spectrum Disorder

1st March 2016

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1. Executive Summary

Interchange Gippsland provides respite and recreation programs for individuals living in Gippsland covering the regional local government areas of Latrobe, Baw Baw, South Gippsland and Bass Coast shires. Limited service is offered in Wellington Shire and East Gippsland Shires. Of the 223 active clients, 77 have ASD, and of the 120 people waiting to access services 67 have ASD.

2. Interchange Gippsland background

Interchange Gippsland provides opportunities to support people with a disability, their families and carers through regular planned respite. We cater for individuals living in Gippsland covering the regional local government areas of Latrobe City, Baw Baw, South Gippsland, Bass Coast local government areas (LGA's). A limited service is offered in Wellington and East Gippsland shires.

- Disability must fit into the broad categories of intellectual, physical, sensory or Autism Spectrum. There are specific eligibility criteria for each individual program such as age, local government area and individual support needs.
- 223 (77 with ASD) active consumers accessing our respite and support programs.
- 120 (67 with ASD) people are on the waitlist, waiting to access Interchange Gippsland programs in the regions of Latrobe, Baw Baw, South Gippsland and Bass Coast. The waitlist operates using our register of need/priority of access system.
- Employ 64 staff (26 EFT), with 79 volunteers (5.3 EFT) and 12 students.
- During 2014-2015 financial year we received 84 new referrals and 91 new participants commenced receiving a service.
- Programs are funded through state and federal government agencies including Department of Health and Human Services, Home and Community Care (HACC) and Department of Social Services (DSS).
- Other funding is received through Latrobe Community Health Service and Latrobe City.
- Sponsors and philanthropic funders include Engie, Apex Club of Traralgon, Latrobe City, Bass Coast Shire Council, CMV Staff Charitable Foundation, and The Collie Foundation.
- Interchange Gippsland self fund programs to enhance service for participants and their families/ carers to enhances their support and inclusion within the Gippsland region.

3. Interchange Gippsland the organisation

Interchange Gippsland want to be recognised as an outstanding provider of flexible, innovative and responsive respite and support services that empowers individuals with a disability and their family. We foster an inclusive Gippsland community where all are respected and have the opportunity to access and participate in activities of their own choice.

Established in 1986 our initial focus was to provide family based respite care services to families who had children with disabilities in the local community. Interchange Gippsland has a long history in the region and we will celebrate our 30th year of operation in 2016.

Over the past 30 years our respite and service options have grown from the Host program in 1986 to now involve a comprehensive number of support services that includes recreational programs, youth

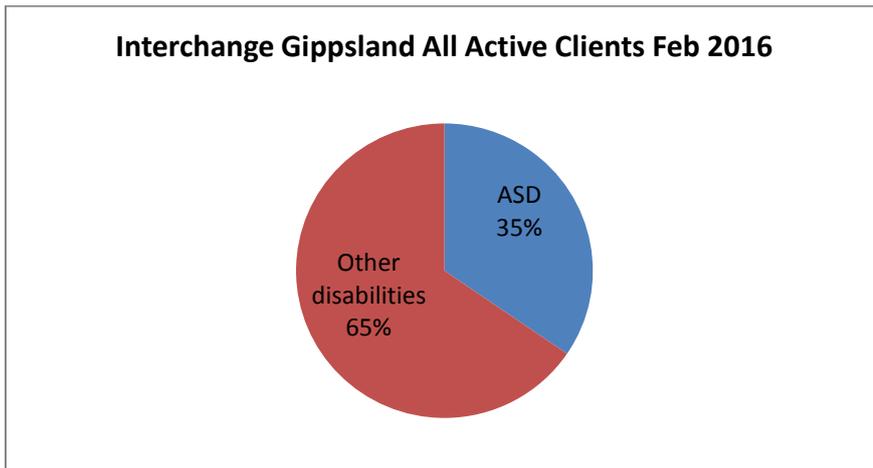
groups, school holiday programs, Young Adults Service (adult day services) purchased care and individual support package management. Services are aimed at providing respite and support for both the individual with the disability and their family/carer. We are a trusted and proven provider of innovative disability support for participants from early childhood right through to adulthood and we will continue to advocate for more services for individuals and families living in the Gippsland area. To date there remains unmet needs in Gippsland with many people living with a disability waiting to access a service.

Interchange Gippsland is governed by a Board of Management of whom 60% must care for a person with a disability. The Board's role is to provide leadership and set the strategic direction of the organisation. This includes approving, reviewing and monitoring the proposed strategy. In addition the Board is responsible for ensuring that Interchange Gippsland complies with relevant legislation and regulations.

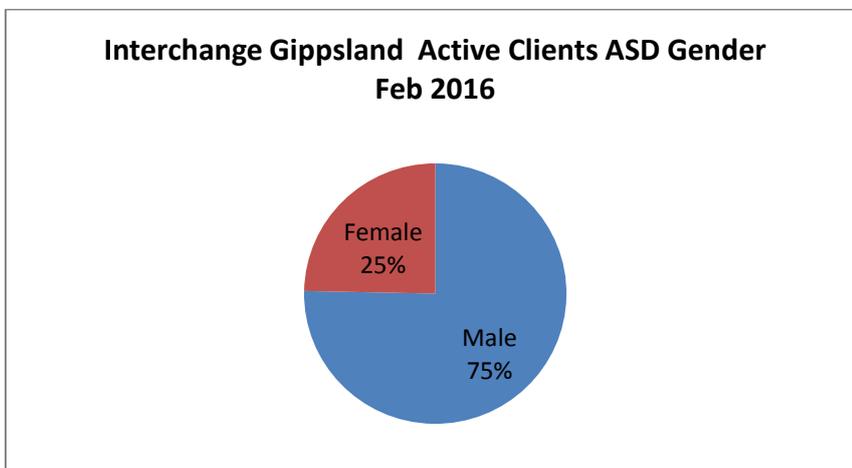
4. Interchange Gippsland participants

223 people are currently accessing Interchange Gippsland's services with 120 waiting for a place on our programs. The total 343 registered participants (active and waitlist) can all access Connecting Families which is a family social support program that Interchange Gippsland provides for all people who are registered with our organisation. This program directly builds social networks and informal supports while keeping waiting participants and their families engaged with our organisation. Connecting Families brings families with similar life challenges together for day and weekend activities. While people have been waiting to access a regular program/group they are able to access Interchange Gippsland Connecting Families activities which consist of annual events, including 3 family days, mother's retreats, father's retreats and a family camp. All of the Connecting family activities are over subscribed and places are based on priority of access. It plays an important role in facilitating social inclusion for families at risk of social isolation. Interchange Gippsland do not keep data on waitlist / register of need for East Gippsland and Wellington Shire due to limited allocation for programs in this area. Interchange Gippsland provided limited support in East Gippsland and Wellington Shire through Aboriginal Family Camp (AFC) and Tracking East, which is open to all the six local government areas of Gippsland. Of our clients receiving a respite service 12% identify as Aboriginal which is significantly higher than national average of 1.64% (ABS data 1.64% of people who have a needs for assistance identifying as Aboriginal).

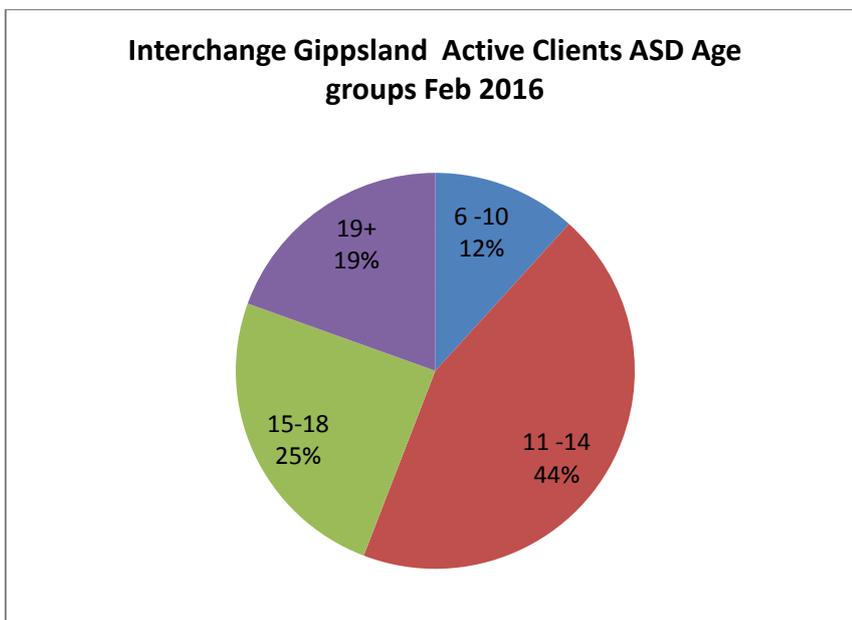
The following table shows the current active clients for Interchange Gippsland by those with and without ASD, of the 223 people accessing Interchange Gippsland services, 77 (35%) have ASD



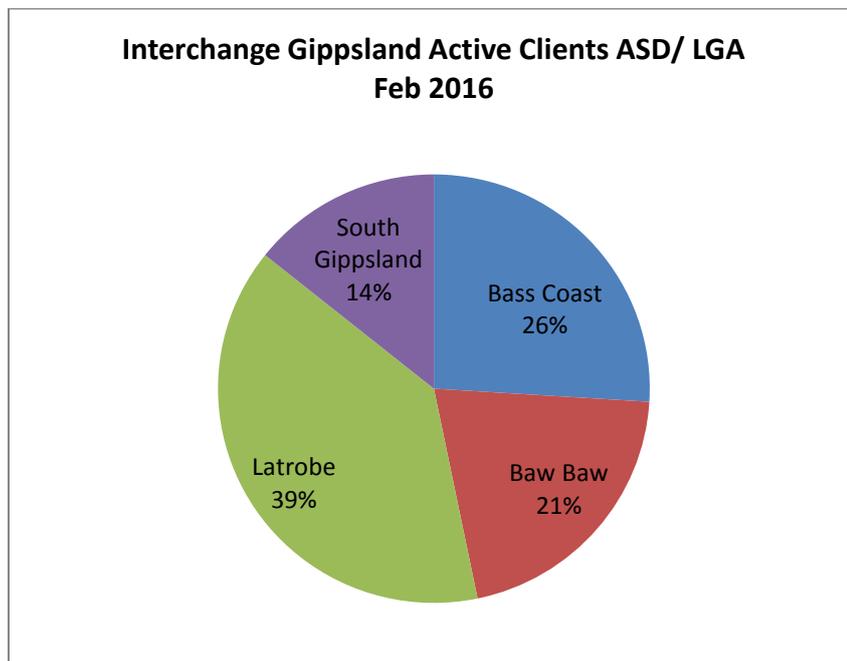
Of those who are accessing a service who have ASD 58 (75%) are male and 19 (25%) are female



Of those who are accessing a service who have ASD zero are under 5 years of age, 9 (12%) are aged between 6-10 years of age, 34 (44%) are aged 11-14 years, 19 (25%) are aged 15-18 years, with 15 (19%) over 19 years of age.



Of those who are accessing a service who have ASD 20 (26%) reside in Bass Coast Shire, 16 (21%) reside in Baw Baw Shire, 30 (39%) reside in Latrobe City and 11 (14%) reside in South Gippsland Shire.



5. Interchange Gippsland Operating Environment

The impact of the current operating environment is influenced by a variety of factors including political, environmental, social, economic, technological and legal. The National Disability Services State of the Disability Sector Report 2014 states that in 2012 – 2013 there were 312,539 people supported by funded services, provided by 2,151 disability support organisations with an average expenditure of \$3.3 million per organisation. On average there are 145 service users per organisation.

The Department of Health released the following profile data in December 2014. The data shows that in 2012, within the Gippsland region, 5% of the population live with a profound or severe disability, compared to 4% of the population for the whole of Victoria. The profile also notes that the percentage of the population, in Gippsland, who are living in the community and have a need for assistance with their core activity living is 6.2% whilst in Victoria it is 5%.

6. Volunteering – innovation in support and social inclusion

Volunteers are critical in the delivery of our programs to participants with disabilities providing social linkages and peer support. As Interchange Gippsland has continued to grow there is increasing pressure to find and recruit new volunteers as well as retaining and engaging existing volunteers in order to deliver our programs and services to our participants and their families.

A professional approach to training and development, support and recruitment ensures we maintain a sustainable approach to their ongoing management, consequently providing a high quality experience for the individuals and families we support. Volunteer involvement in our programs provides many benefits to participants such as social inclusion, assistance with participation in an activity providing the participant with a sense of empowerment and an individual quality and responsive experience.

The inclusion of volunteers on our programs assists participants to be active in our local community, fostering a sense of belonging and feeling of increased safety. Our innovative use of volunteers means participants receive an individualised and personal support and respite service and peer support. Volunteers also actively assist families with respite (time out) from their full time role as a carer. A simple occasional break helps build social structures within our community, giving families time to recharge their minds and bodies enabling them to continue with the demanding role of being a carer for a child or young person with a disability.

Volunteers are age appropriate and can be broken down into two groups – teenage (under 18) and adult (over 18). Ongoing training and support is provided to all Volunteers. We also have an established reward and recognition program for our volunteers.

There are many benefits to volunteering both individually and for the community. Volunteers are future community leaders, they help make the Gippsland region more inclusive, understanding and supportive. They play an active role in building community capacity and their involvement is greatly valued by our participants and their families.

7. Programs that have waiting lists/ unmet needs

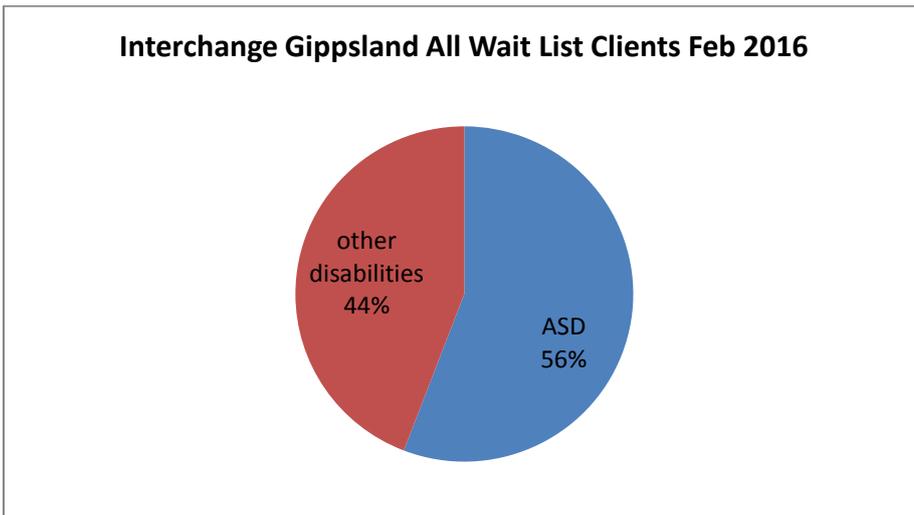
Interchange Gippsland is predominately block funded with the exception of YAS (Young Adults Service), which provide individualised supports to people with a disability in a group setting using DHHS funding of Individualised Support Packages (ISP) or Futures For Young Adults (FFYA).

Long waiting lists apply for all programs that are block funded. While participants and families are waiting to access a regular service they are able to access the Connecting families activities. It is anticipated that once people are funded individually under NDIS it is expected that their care needs will be met. The Interchange Gippsland suite of programs is highly sort after by people with ASD and their families.

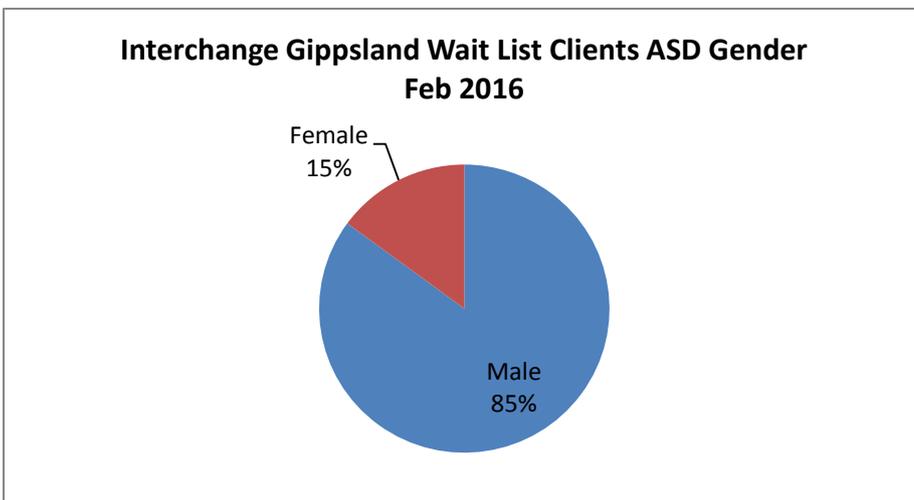
Interchange Gippsland Programs that have waiting lists

1. HoP – Holiday Options Program is a recreation and respite program for 10 -13 year olds.
2. ROADIES – Respite Options for Adolescents with Disabilities in Enjoyable Situations. A respite and Recreation Program for 14- 17 year olds matched with a teenage volunteer and supported by paid staff.
3. Friendship Group – Supported monthly social outings for adults with disabilities aged 18-30 years (participants pay for their own activity. Interchange Gippsland arranges activities and provides Support Workers and adult volunteers).
4. Friends for Life (FFL) – Weekly supported social outings for adults with disabilities aged 30- 65 years. Participants pay for their own activity. Interchange Gippsland arrange activities and provides Support Workers and adult volunteers.
5. Mothers Retreat and Fathers Retreat – supported respite weekend away for carers of individuals with a disability. Provides an opportunity for parents to share experiences and develop long lasting networks.
6. Family Camp – Annual camp that includes person with a disability and their carers, provides an opportunity for all to share experiences and form friendships and networks.

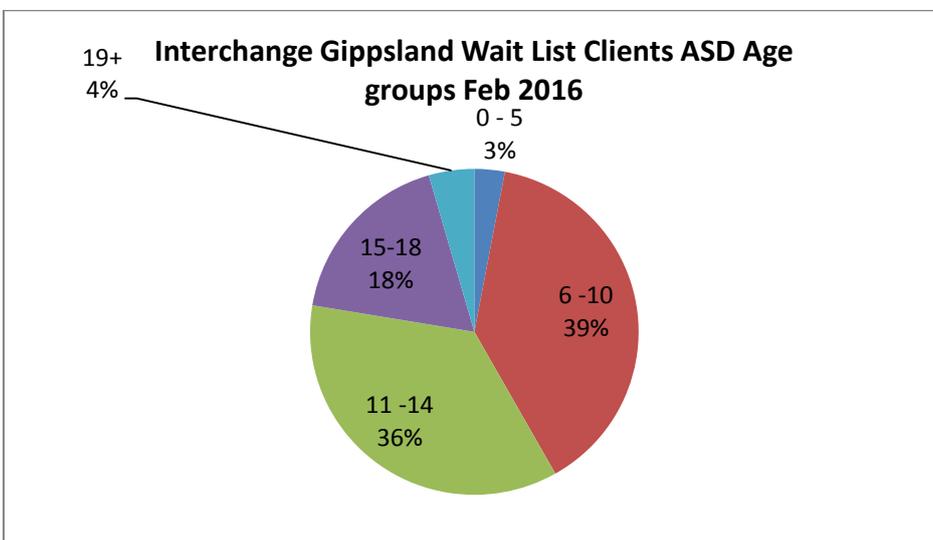
The following table shows the current wait list for Interchange Gippsland by those with and without ASD, of the 120 people waiting to access Interchange Gippsland services, 67 (56%) have ASD



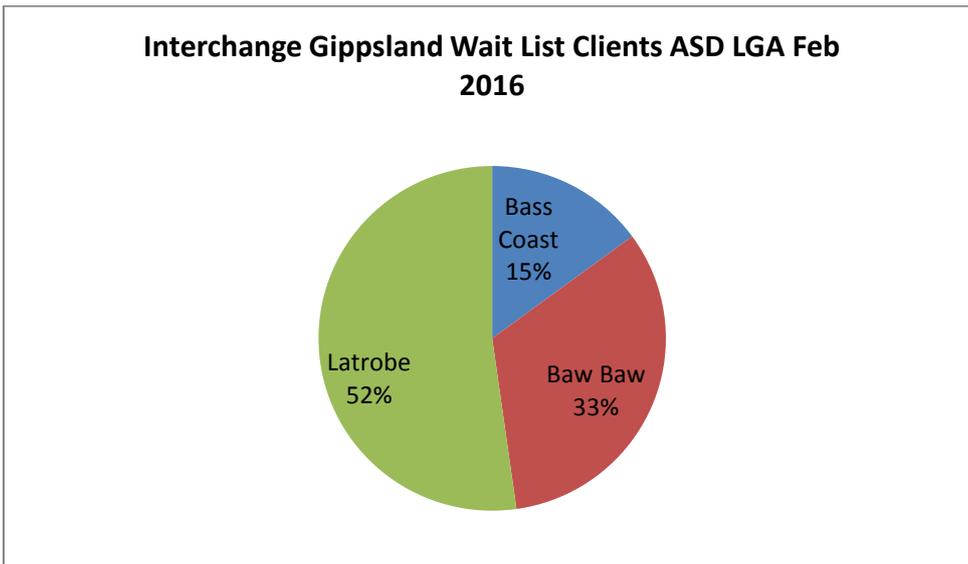
Of those waiting who have ASD 57 (85%) are male and 10 (15%) are female



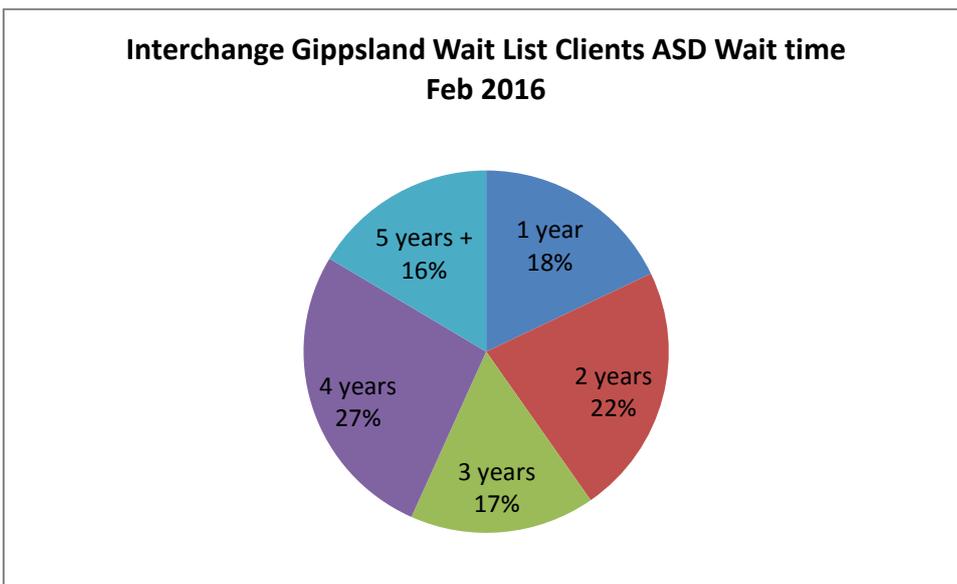
Of those waiting who have ASD 2 (3%) are under 5 years of age, 26 (39%) are aged between 6-10 years of age, 24 (36%) are aged 11-14 years, 12 (18%) are aged 15-18 years, with 3 (4%) over 19 years of age.



Of those people who are waiting who have ASD 10 (15%) reside in Bass Coast Shire, 22 (33%) reside in Baw Baw Shire, 35 (52%) reside in Latrobe City.



Of those waiting who have ASD 12 (18%) have been waiting to access services for 1 year, 16 (22%) have been waiting 2 years, 11 (17%) have been waiting 3 years, 18 (27%) have been waiting 4 years, with 11 (16%) have been waiting for over 5 years.



Appendix 1 – Client Case Study Unmet Needs

Participant – David, 20 year old male living in the Gippsland Region

Please note: for the purpose of this case study the participant has been de-identified and real names have been changed to protect privacy.

David is an Interchange Gippsland participant. He is living with severe Autism, an Intellectual Disability and Obsessive Compulsive Disorder. He is in the sole care of his aging, widowed, grandmother Mary and he has very limited family supports. Both of David's parents have not had contact with him for numerous years. Mary tries incredibly hard to give David the best possible life, however she also has ongoing health issues of her own. In addition to being David's Primary Carer she also provides support to her elderly mother. They both receive Centrelink payments which is their only means of financial support.

As David's fulltime carer, Mary manages all his medication, she supports him with all bathing and personal care, she prepares all his meals, to which he has a very particular diet. Mary's role of fulltime carer is incredibly stressful and she constantly worries about his future knowing that David cannot be left unattended. Mary has not been able to have overnight respite for over three years due to David's presenting behaviours of concern in a respite home setting and limited access within the community. Mary is unable to leave David unattended. She is physically unable to manage David's behaviours at times and cannot take him out into the community. David has caused much damage to Mary's home, with the house having many holes in the walls due to David's physical outbursts caused by his disabilities. At times Mary feels physically threatened by David's behaviour as he towers over her in size and stature. While Mary receives respite for 6 hours from 9AM – 3PM Monday through to Friday during school terms, she mostly must fend for herself at night, during school holidays and on weekends leaving her isolated, vulnerable and alone to cope with young man with extremely complex support needs. Respite support on weekends and holidays is limited. Mary receives only 3 hours respite on weekdays and Saturdays and only 4 hours on a Sunday. Mary's personal health is deteriorating and she needs time to care for her own needs. She is in constant worry about David's future as he is still a young man who has a lot of living to do and he is likely to live another 60 years.

David is a large and physically imposing man and he is extremely strong. He has very limited single word verbal communication and uses a communication book to assist him to express his needs. David uses some limited signing in an attempt to communicate. His disability sees him requiring significant staff support to function and he needs lots of firm and ongoing encouragement to use his communication book effectively. David regularly becomes frustrated when he cannot communicate his needs. This results in him banging his head with his fists and on walls, crying, pushing/poking others and stomping around. To improve David's life he requires a clear 'daily routine'. Any changes to his daily routine need to be introduced carefully and in a planned and gradual fashion as it takes time for him to process and accept changes in his day to day routine. David's resistance to change makes it very difficult for him to be part of group situation or included within the community. He requires individual supervision just to manage his obsession with plastic items. His obsession with plastic when out in public at times puts David at risk as he becomes fixated on seeking out these items in inappropriate or unsafe places. At home David's Grandmother Mary must keep things locked away. When David sees a plastic item he wants it is very difficult to stop, restrain or distract him from achieving his aim. He has a limited concept of 'other' possessions and will stop at nothing to achieve his objective. David will enter handbags to seek plastic items, road work areas and has entered shops to remove plastic lids and items. When he gets hold of the items he will often place them in his mouth and has been known to break them with his teeth, this can include items such as knives with plastic handles and drink bottles. Due to his physical size and strength David is incredibly difficult to manage in these situations. He can be very intimidating to members of the public and people who do not understand his obsessions and disabilities. Some incidents involving David have included entering a car with a small child in it at a public park to remove a drink bottle off the child causing considerable stress and fright to both the small child and the mother. David has attempted to exit moving vehicles to get to plastic roadworks signs and equipment which put his personal safety at risk. Another incident saw David attempt to break into a petrol station through a large plate glass window to access a plastic item on the other side. This caused great stress and fear to the female worker. David's behaviour has caused such concern in the community the police

have been involved. His behaviour is unpredictable and community members feel threatened when he approaches.

Due to the nature of David's behaviour management plan many settings are avoided to protect his and other people's safety. He has limited capacity to risk assess, and he needs constant 1:1 supervision. His limited social skills makes it incredibly difficult for him to engage with others in a group setting, although he really likes to be out and about in a social setting. Interchange Gippsland has worked hard to assist David's social opportunities, although this is limited due to his needs. As a result David is socially isolated. He has no other social opportunities outside attending Interchange Gippsland's Young Adult Service.

Until Interchange Gippsland, David had been previously rejected by several other disability service providers due to his high and complex support needs. Throughout his lifetime David has been assessed by various organisations and access to service has regularly been denied and rejected as he is deemed as not being group suitable. He is attending Interchange Gippsland's Young Adult Service 5 days per week from 9am – 3pm and he requires 1:1 support although he is not funded to this level.

David has had his SNA level reviewed 3 times in the last 12 months. On each occasion it has come back at an unsatisfactory level, it does not reflect the level of support David requires for his behaviours of concern. This has been included in his DSR application. David has an active DSR application for his Individual Support Package (ISP, with significant concerns identified around his current level of funding for respite not being sufficient to support the stressful and fragile carer relationship and home situation. It also calls for ongoing 1:1 supports at YAS.

David has had a recent Speech therapy assessment and a sensory assessment, the reports have been finalised but without a further avenue for funding the outcomes of these assessments will fall to Interchange Gippsland staff to interpret and implement as further sessions with the Speech Therapist and Occupational Therapist are not affordable for David and Mary.

These assessments were a requirement for an emergency funding application that we completed with DHHS for David. This emergency funding was to help Mary over the Christmas and New Year period of YAS being closed and David being home 7 days a week for 4 weeks and to have DHHS Specialist Services involved. Their involvement is to assist Interchange in developing some support strategies to use in the hope that we can increase his group and community inclusion. This to date has not happened, Specialist Services are still arranging times to come and meet David and do some observation and data collection. The emergency funding received will run out in April 2016 with current support levels remaining as 1:1.

The current funding to support David is inadequate. Specifically he receives \$28,496 for his Individual Support Package for respite and \$28,568 from SNA 4 from Future for Young Adults. This equates to a total of \$57,064. Interchange Gippsland are providing 1:1 support in day service without the funding reflecting David's required support. His current funding is registered as SNA 4 when his funding SNA should be elevated to the highest possible and categorised for 1:1 support. David has had his SNA reassessed by a phone questionnaire and there has not been an assessment that has involved meeting David and seeing how he is struggling within the community. This last assessment (in February 2016) has resulted in no change to his ongoing funding level. His current funding is not sustainable for Interchange Gippsland, but as a needs based disability service organisation we are aware if we refuse to provide David a service there are no other options available to meet David's and his Grandmother needs. This would leave David and Mary at risk if unsupported, seriously compounding their issues of social isolation. Mary has been quite open with her conversations that if David is refused a service from Interchange Gippsland she will need to make that difficult decision to relinquish his care to DHHS.