

East Gippsland Respite Survey

Save the Children Australia have recently conducted a survey from December 11, 2018 until February 22, 2019 with 34 respondents, assessing the support available/utilised by families.

Key Results

- It is the children of the family surveyed that require support (68%)
- Typically, male (78%) children, aged 7-12 years (44%)
- Adults requiring support only accounted for 22% of respondents
- Autism Spectrum Disorders (ASD) is by far the most common disability stated
- Overwhelmingly, families are not getting the support they require (81%)
- A large and varied range of social and community participation activities have been suggested for the families surveyed – recreational activities, day camps, outings, social groups, supported holidays, parents retreat are amongst the popular ideas
- In terms of regularity, fortnightly assistance (66%) and during school holidays (53%) were commonly required for social and community participation.

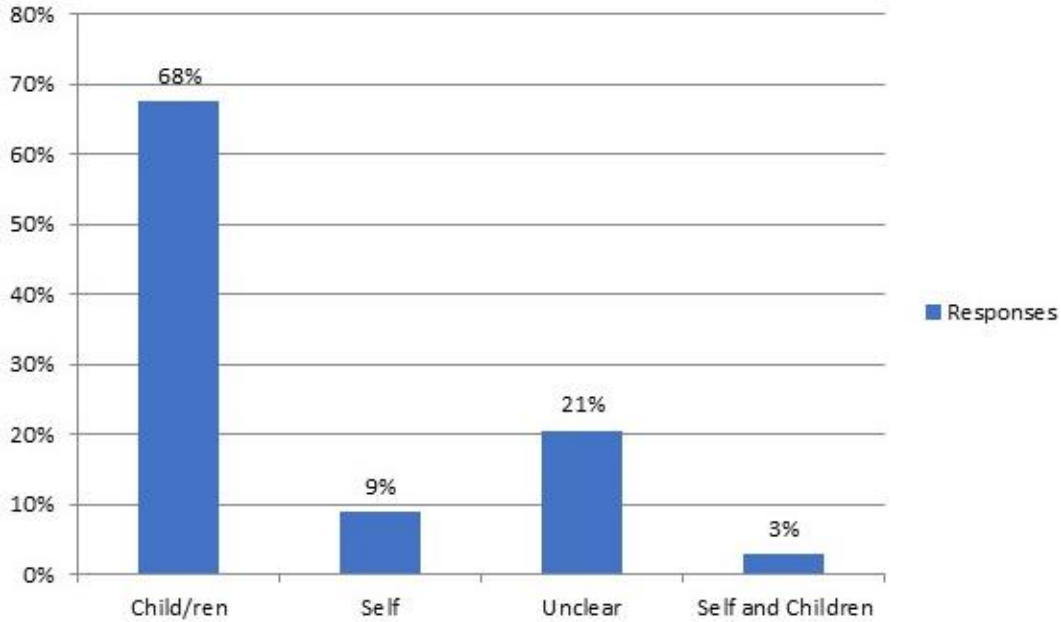
Key NDIS Category Results

- In the category of 'Independent Living Skills', assistance with daily living (88%), followed by improved health and wellbeing (69%) are in the greatest need
- Similarly, in the category of 'Capacity Building (build the skills of the individual)', improved daily living skills (91%), followed by improved health and wellbeing (75%) are also in the greatest need
- In relation to 'Assistance with/Increased Social and Community Participation', support is required during school holidays (74%), followed by before and after work (61%) and during the day on the weekend (61%).

Survey Data

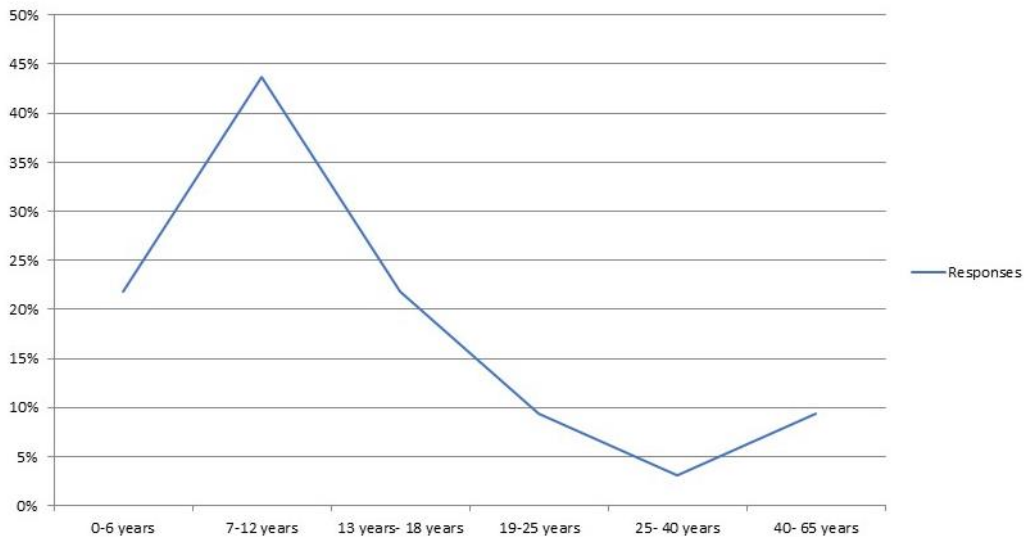
The following outlines all survey questions and responses. Some reported data has been altered to ensure that no information is people identifying.

1. Who will use/requires support (previously known as respite) in your family?

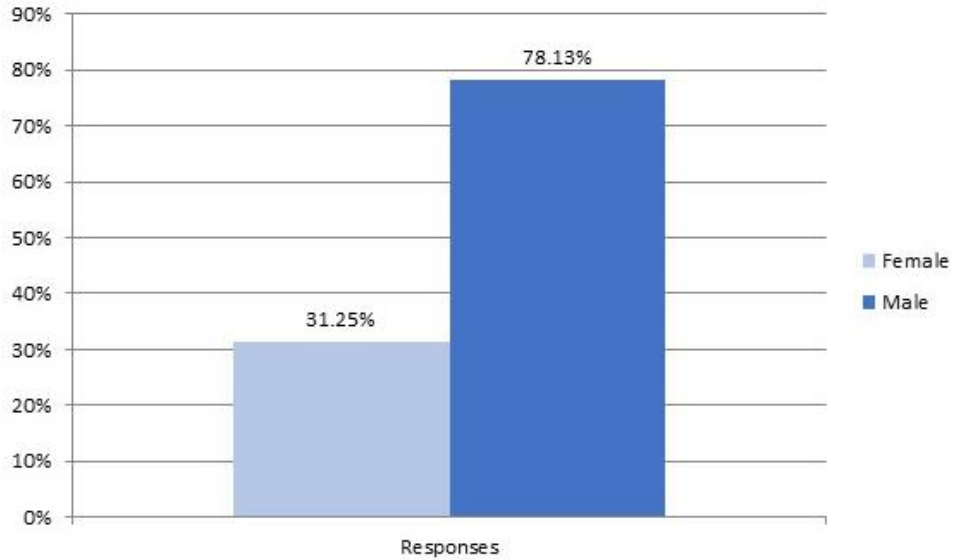


Note: This survey question was asked as a text response, making it difficult to interpret the responses. The writer has attempted to categorise the answers, with unclear responses categorised as such. Survey data for this question is obtainable but withheld from this report due to number of responses containing identifying data.

2. How old is the person that needs to access support (or respite)?



3. Gender



4. Please tell us about your disability and/or needs for you or your children who require support (or respite)?

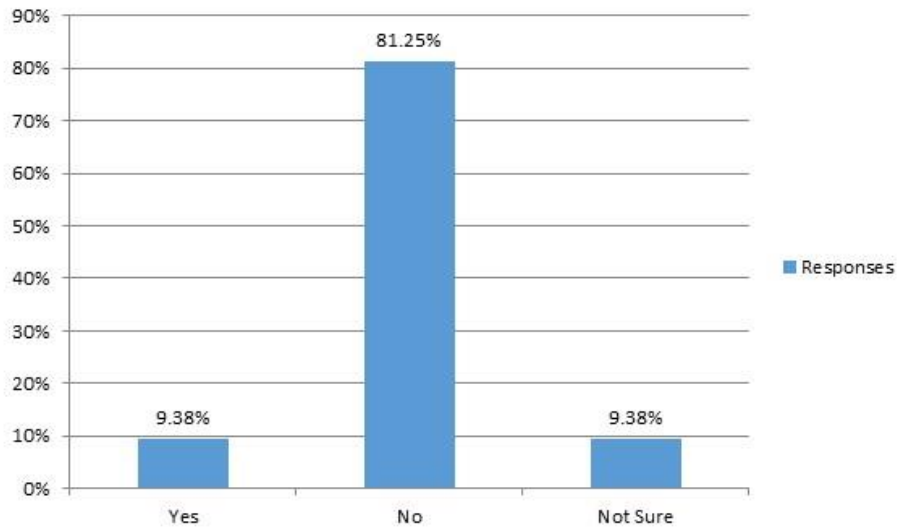
This survey question was asked as a text response, making it difficult to interpret the responses into categories. All data is therefore outlined below. The writer’s interpretation is that Autism Spectrum Disorders was overwhelmingly the most common response, followed by Intellectual Disabilities, Attention Deficit Hyperactivity Disorder, Sensory Processing Disorder, Anxiety and Dyspraxia.

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| 1. Intellectual disability, epilepsy and autism. Still not toilet trained. |
| 2. ASD & anxiety disorder. Suffers long episodes (months or years) of separation anxiety, triggered by trauma, unexpected change or sensory overload. |
| 3. Autism spectrum disorder |
| 4. Autism, mild intellectual disability |
| 5. Autism, ADHD |
| 6. ASD, ADHD, significant language delays (expressive & receptive) |
| 7. ADHD, Anxiety, Learning difficulties |

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| 8. Intellectual disability and autism |
| 9. Autism |
| 10. Autism, sensory processing disorder, major depressive disorder, PTSD, anxiety & osteoarthritis |
| 11. Autism with an intellectual and mild physical disability |
| 12. Cerebral palsy, Profound deafness, Manual wheelchair, very little communication |
| 13. Access community |
| 14. Requires 24/7 care with all ADL. Has a neurological regression syndrome so increase in care needs is expected. Currently accesses respite in Sale. Approx 6 times a year. |
| 15. Autism, epilepsy and global development delay |
| 16. ASD |
| 17. Severely autistic non verbal child, support requires changing dirty nappies feeding and 1:1 support at all times |
| 18. Spondylosis and right side injury affecting all of right side and interfering with mobility which makes me very isolated socially and in turn makes my carer family member also isolated |
| 19. Level 3 Autism with an Intellectual Disability. My Partner and I are the only carers for our child and we need some time with our other child as this never happens |
| 20. Autism and low cognitive function, who requires someone to help communicating their needs and if alone, can't ask for help can be lost easily, if over whelmed can become violent, needs to learn to do things without mum |
| 21. Autism with an ID. Need support with behaviour challenges and we all need regular breaks to keep on, in this caring role. |
| 22. Autism & ADHD |

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| 23. Autism |
| 24. Diagnosis of ADD, ADHD and anxiety. Respite required to give family some time to plan and organise house to accommodate behaviours. Has impact on family wellbeing and physical harm to his brother. |
| 25. Autism - needs interaction with people |
| 26. Potentially ASD, sensory processing, social play, dyspraxia. |
| 27. ASD, sensory processing, social issues, dyspraxia. |
| 28. ASD, sensory processing, behavioural issues, social issues, dyspraxia. |
| 29. ASD, sensory processing, behavioural issues, social issues, dyspraxia. |
| 30. Both children with ASD, special needs |
| 31. Autism and psychosocial disability requiring respite from my child with a disability, so I can maintain and increase my functional capacity to work. |
| 32. Phelan-McDermid Syndrome with severe autism |
| 33. Mainly ASD |
| 34. Phelan-McDermid Syndrome with severe Autism |

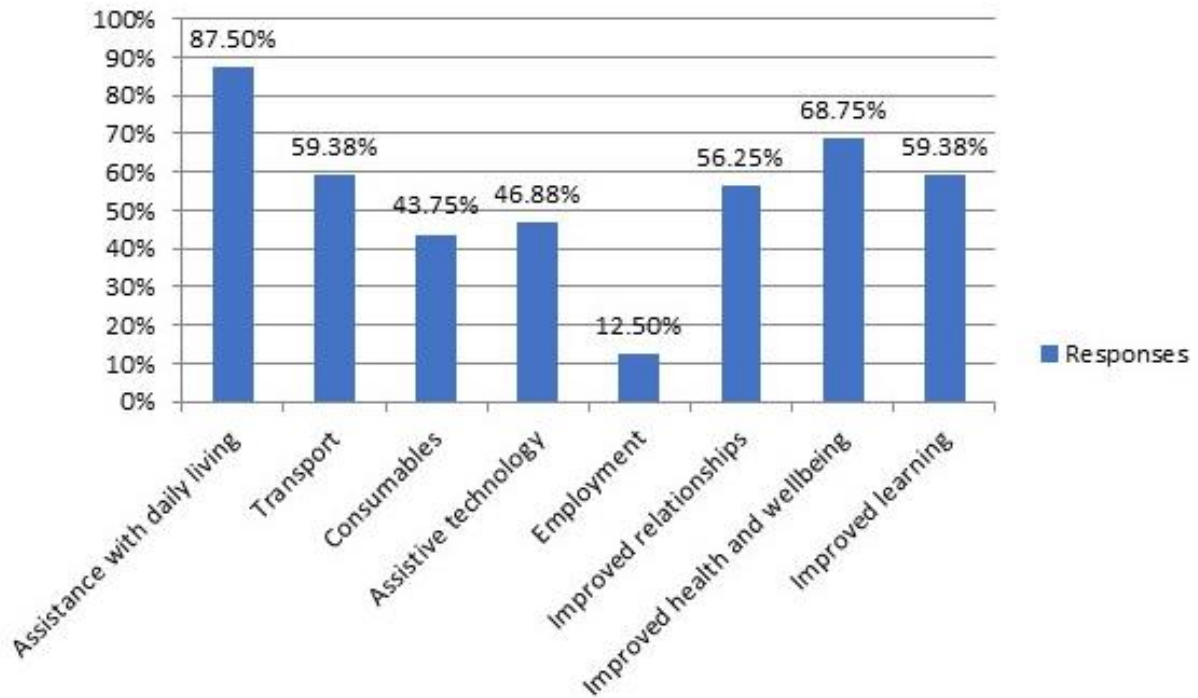
5. Do you currently get the support (or respite) your family requires?



Further responses provided:

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| 1. Informally, through family and people we pay privately |
| 2. We have just started respite in sale and its not working and the drive is too far. |
| 3. Would be good if it was more regular and consistent |

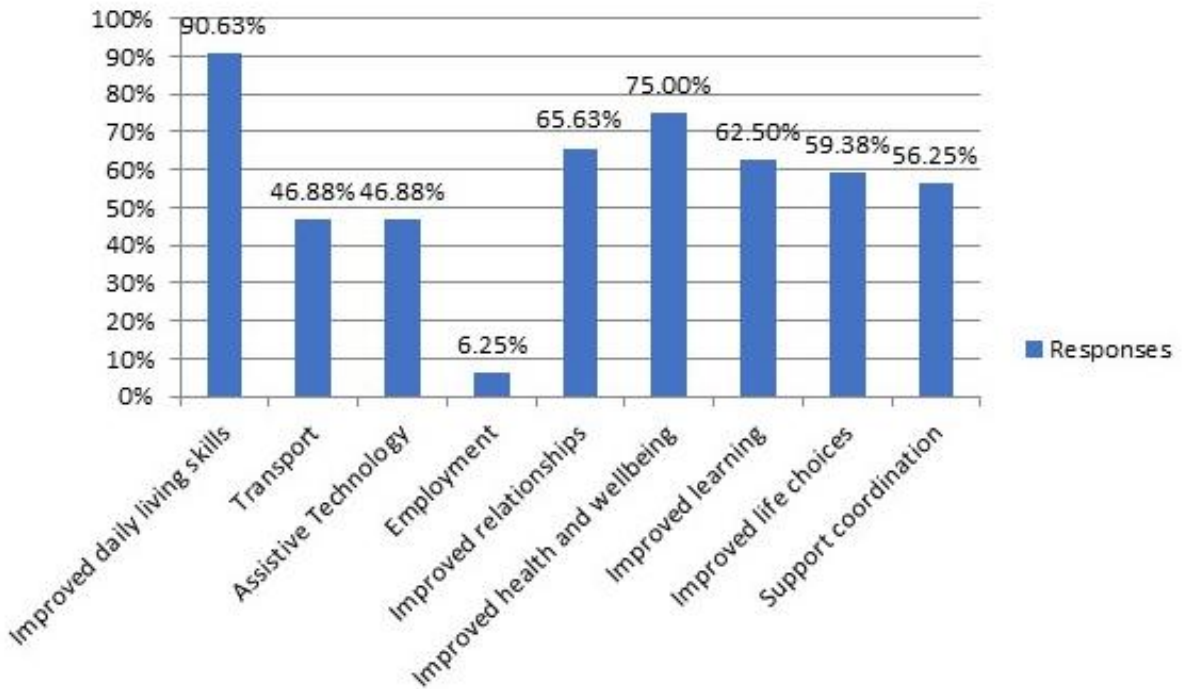
6. Please choose your needs in the following areas. Please note these areas are the categories that are under the NDIS. The first is Independent Living skills. Please select what supports you need under this area.



Further responses provided:

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| 1. Improved independence |
| 2. More family time |

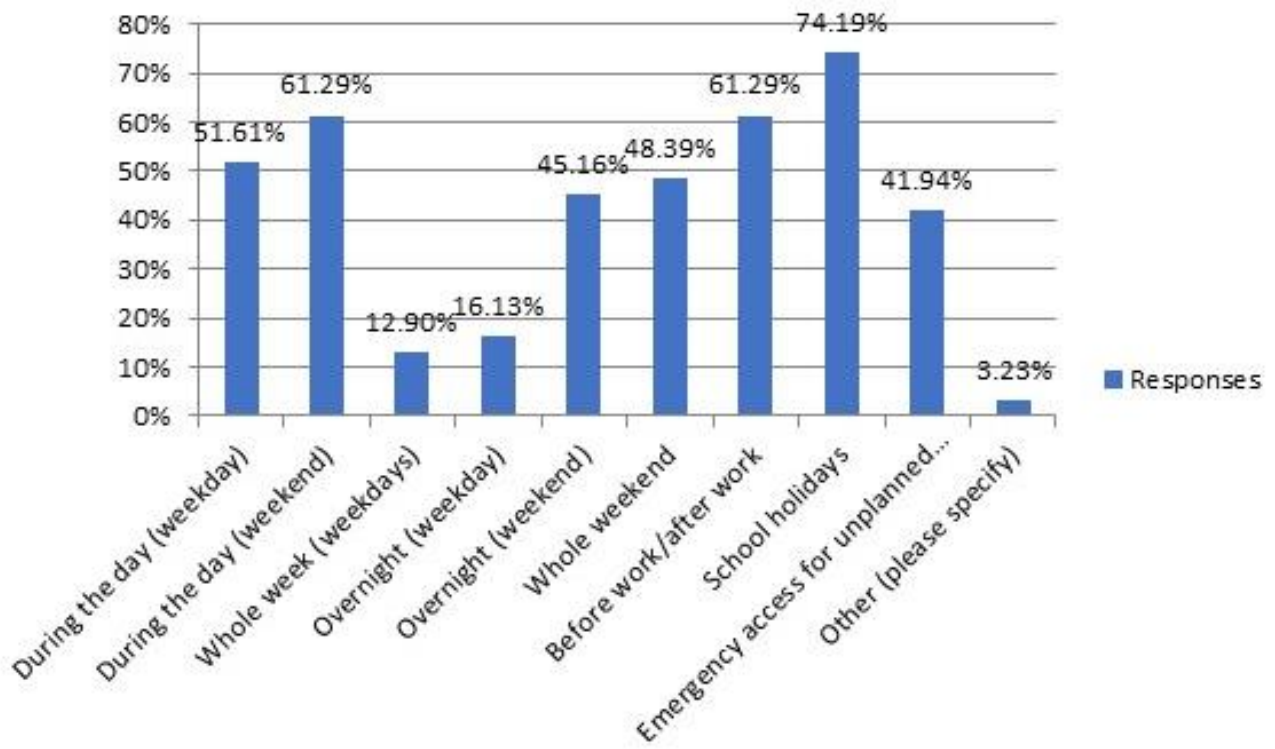
7. Please choose your needs in the following areas. Please note these areas are the categories that are under the NDIS. The second is Capacity Building (build the skills of the individual). Please select what supports you need under this area.



Further responses provided:

1. Improve my functional capacity to manage work

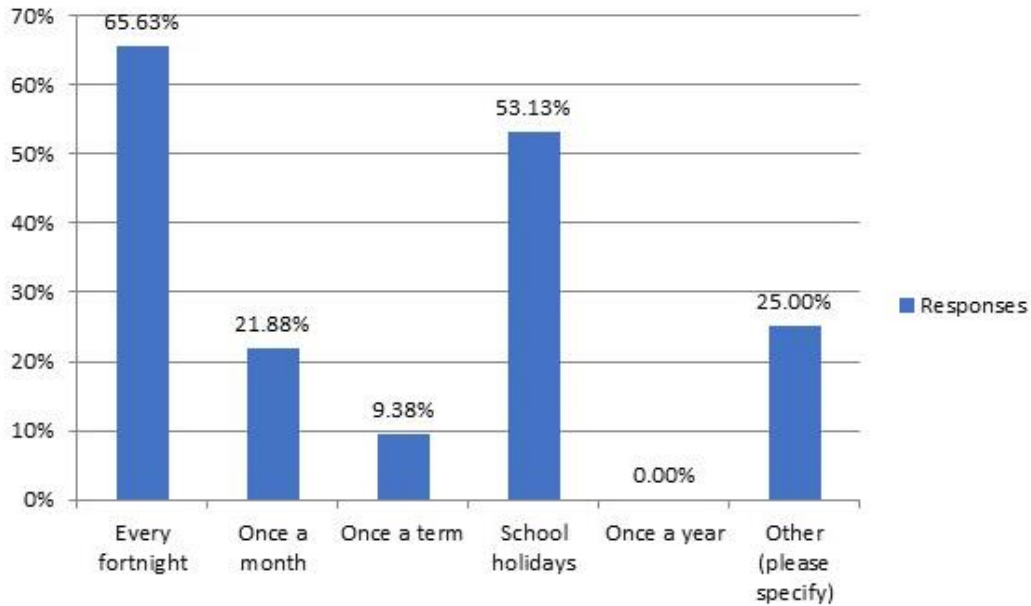
8. Please list your needs in regards to respite, which is 'Assistance with/Increased Social and Community Participation' under the NDIS.



Further responses provided:

1. I can never go to funerals or into hospital for emergencies because I have no one to take over my role at home with my child who also has a disability

**9. How often do you need assistance with social and community participation?
(please note most families may be limited to 28 days per year, please check with
your planner)**



Further responses provided:

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| 1. Every week |
| 2. Weekly. Currently have sports in place to help build and maintain positive relationship/ friendships with peers. |
| 3. Weekly |
| 4. Every week |
| 5. Every week |
| 6. When taking child out to events |
| 7. Every week |
| 8. We have respite allocated but the services are out of town and have not been accessed for two years because my child was bashed twice in the DHHS holiday respite facility. It is also too clinical and sterile and should be offered within the home so that the things they require, are around them. I personally have no group respite to access at all that meets the needs of myself if my child does access respite. There is nowhere for me to go and I do not have the funds to do anything being on a DSP. |

10. What sort of social and community participation activities are you seeking for yourself or your child/ren and family? (day camps, recreational activities, art, drama, music, social groups, family camps/activities or supported holidays, parent retreat, outings to the movies, etc.)

This survey question was asked as a text response, making it difficult to interpret the responses into categories. All data is therefore outlined below. The writer’s interpretation is that recreational activities, followed by day camps are amongst the most popular ideas. Outings, social groups, supported holidays, and parents retreats also appeared frequently.

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| 1. Someone to take child to after school all abilities group and stay with them (help get dressed, etc). Someone to take child out on weekends. |
| 2. Parent retreat, social groups |
| 3. Outings, day camps, recreation activities |
| 4. Music, sport |
| 5. Movies, school holiday activities, parent retreat, supported holiday |
| 6. A weekly event that he can attend to learn a new skill whilst developing and maintaining friendships with his peers. School holiday camp. He has really missed having his independence. Parents retreat; to allow us to recharge, personal development as a carer. Family camp; we go away camping and on holidays as a family, throughout the year. But this is additional, it allows the whole family to get together with supports to make it vastly more enjoyable and relaxing. It also increases social participation for the whole family, with his sister making friends who live a similar life. |
| 7. Family camps |
| 8. day camps |
| 9. Camps, family camps, holidays, parent retreats, outings, one on one bonding, social groups, equine therapy, swimming, day activities, recreational activities, family outings, art, music, school events, disability specific events in Melbourne e.g.: special children's Christmas party & variety Christmas parties, dream night at the |

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| Melbourne Zoo, aquarium, Werribee Zoo, Gumbuya world, Healesville Sanctuary, Mt Hotham snow trips, Scienceworks and many others. |
| 10. Social. Supported holidays parent retreats. |
| 11. Outings; recreational activities; supported holidays |
| 12. Outings supported holidays Social groups |
| 13. Supported holidays recreational activities |
| 14. Social activities and more outings |
| 15. Family activities, outings, swimming lessons, social groups, Girl Guides, community access library, recreation activities |
| 16. Day camps, activities , art , music , social groups , supported holidays and parents retreat plus outings , movies all excellent programs for our family |
| 17. Outings to movies, recreational activities |
| 18. Support for holiday program, activities and family outings |
| 19. Day camps, supported holidays, outings, going to big events |
| 20. Physical activity for 1:1 need Inclusion activities that involve practicing life skills like shopping Social skills/ regular supported friendship group |
| 21. All I of the above suggested - activities and growing opportunities to develop independence. At the moment my son is completely reliant on his immediate family and we have no other support. |
| 22. Recreational activities, outings to the movies |
| 23. Preferred is drama/dance and day activities |

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| 24. Camps, participating in weekly sport, attending annual community events or school holiday activities (movies, ranger activities, library activities), parent retreat sounds good! |
| 25. Various activities during the day and skill building opportunities. |
| 26. Day programs or assistance with appointments and skill building |
| 27. Day camps, recreational activities, social groups, supported family camps |
| 28. Day camps, social groups, supported family camp, supported holidays. Parent retreat would be wonderful but not sure how it would be paid for. |
| 29. All of the above mentioned activities |
| 30. All of these activities such as camps, recreational activities, art, drama, social groups, family camps and activities or supported holidays would make a huge difference if they were available in East Gippsland. If they were available I could access them on my plan to improve my informal supports/networks whilst improving my functional capacity to manage work and increase better relationships and improved communication and social reciprocal interactions with others. I just want to be included and participate in the community. |
| 31. Recreational activities, social groups, outings |

11. Contact details. Having family information will assist us to advocate for the services and programs that families need. We will only pass on your details to potential service providers or to get further information.

Information obtainable but withheld from this report due to identifying information.

12. Please share any additional needs or comments in regards to support for your family.

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| <p>1. We have always used informal supports, eg sister or grandparents. But in 1 year, the sister will move away for university (as with rural students heading off to uni). Secondly grandparents getting older and one no longer driving. I can only work school hours and cannot increase my hours due to having to be at bus stop to pick son up as no respite worker to assist. Luckily my work offer 48/52 scheme to help me convert school holidays but with daughter off to uni, my work may be an issue. I am concerned that due to changing informal supports (daughter off to uni and grand parents getting older and no longer driving) my husband and I will end up tag teaming our holidays just so we have someone with the child during school holidays... and end up having no time off at same time. There needs to be school holiday respite available for working families</p> |
| <p>2. 5 out of 6 members of our family have a diagnosed disability. 4 are NDIS participants. This compounds the need for respite-type support.</p> |
| <p>3. It has been important for the siblings to have some respite. Having an option for siblings / the whole family would be very helpful.</p> |
| <p>4. More supports for father's who having a carers role. Something relaxed and social.</p> |
| <p>5. We are a very complex family with complex needs. NDIS is so individualized that it makes it extremely difficult to be able to have a planning meeting with all family members at one time because there are so many LACs!</p> |
| <p>6. Cooking and reading lessons</p> |
| <p>7. Need more family time with other kid and wife</p> |
| <p>8. Keep play connect going and my time group with more funding for parent experiences - Bus organizer / funding for Melbourne disability events. For services to make themselves known by attending my time groups etc</p> |

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| <p>9. Would love to have short accommodation in Bairnsdale as I work night shift and driving to sale and staying there for 3 hours is really not worth me going. We are trialing it but its just too far.</p> |
| <p>10. Siblings are not provided any support in our area due to lack of funding and a perceived, not high enough demand, for a service to them to be provided.</p> |
| <p>11. It has been very difficult to get consistent services and medical care in this area. Services have also been difficult to access as there is not enough qualified or experienced practioners here. Wait times for appointments are frustrating especially when our need has been high and stressful. Also to finally get to these appointments and find inexperienced practitioners or inflexible practitioners, that are not able to work with the family dynamic or with children's specific needs.</p> |
| <p>12. Support by way of resources (books/workshops/seminars that run on weekends) as we work full time. We can't access seminars currently as they are during the day</p> |
| <p>13. These school holiday have been PAINFUL! Would be amazing to have a day program that has autism friendly activities and trained staff.</p> |
| <p>14. I have had little opportunity for informal supports in the community. If you have a mental illness you are unable to access regular case management/ supports from Gippsland Lakes Community Health Service and your only option is Within Australia. This service has not been meeting the needs of their client base and has few opportunities for social interactions. There is little awareness that transport has to come out of the pocket of the individual requiring people on a pension to be excluded from activities just because of travel expenses associated with accessing programs and services. If we don't have the services and programs available here how are we to access them to truly participate and be included in our communities...a major dilemma here in East Gippsland. Please help.</p> |
| <p>15. Access to equipment</p> |
| <p>16. The families in this region are limited with the support they are able to access due to the rural nature of East Gippsland.</p> |
| <p>17. Greater access to supported community participation</p> |