

CHILDREN WITH ADDITIONAL
NEEDS WORKING GROUP

East Gippsland Community Support Proposal:

"Community Connection Role"

A ROLE TO HELP FAMILIES NAVIGATE SUPPORT AND
NDIS PATHWAYS, WORK WITH PARTNER PROVIDER
SERVICES IN
EAST GIPPSLAND AND ENABLE INNOVATION IN THE
REGION.



*Children With Additional Needs
Working Group*

The Children with Additional Needs Working Group (CWANWG) is a sub-group of The Children's Wellbeing Collective (a partnership of agencies overseeing the East Gippsland Early Years Plan and the Children's Wellbeing Initiative and providing guidance for the Communities for Children Program). The Children's Wellbeing Initiative emerged to support community responses to the data highlighted in the Wellbeing of Children and Young People Report (first published in 2013 and then replicated in 2018). A copy of the report can be found here:

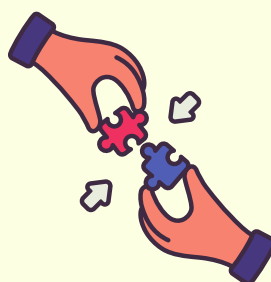
https://www.savethechildren.org.au/getmedia/cc1f94fc-8907-41c8a9f6d470d01ce177/East_Gippsland_Wellbeing_Children_Report.pdf.aspx

The Children's Wellbeing Collective receives recommendations from the CWANWG, which identify issues for children with additional needs and their families and how improvements can be made. This group meets monthly and has been successful in giving families and services a platform for a variety of issues. The purpose of the CWANWG is to work together to support families with children with additional needs in East Gippsland with a focus on integration, coordination and communication. The working group is underpinned by the vision and outcomes of the East Gippsland Early Years Plan and the Communities for Children Community Strategic Plan. Membership consists of service providers and families. The following organisations are part of the CWANWG: community members, Save the Children, Uniting, Gippsland Disability Advocacy Incorporated, Playgroup Victoria, Noah's Ark, Department of Education and Department of Health and Human Services, and Latrobe Community Health Service.

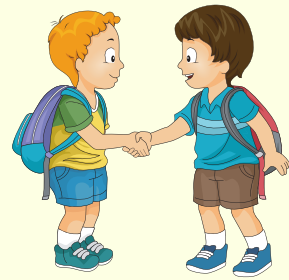
The outcome the CWANWG is focused on is: **Children with additional needs get what they need to support their development.** This outcome is outlined in the Children's Wellbeing Collective's action plan and program logic. The CWANWG reports to the East Gippsland's Children's Wellbeing Collective (CWC). The CWC is a key partnership that focuses on a strategic approach to improve outcomes for children in five key priority areas in East Gippsland.

In order to achieve the longer term outcome outlined above, the CWANWG focuses on a series of objectives:

- ✓ Strengthen services ability to engage and work with families with children with additional needs
- ✓ Enhance communication between services and with families with children with additional needs
- ✓ Ensure that all activities are informed by best practice
- ✓ Consult with families with children with additional needs about their experiences accessing services in East Gippsland
- ✓ Make recommendations and advocate to the broader Children's Wellbeing Collective and relevant funding bodies on strategies to improve the provision of services and supports for families with children with additional needs in East Gippsland.



The CWANWG have identified that there is a deficit in support for families in East Gippsland. What is missing for families is the available information to access support and services (whether they are eligible for NDIS or not). The support for families who do not fit the criteria for the NDIS has been a concern of the group for some time. There are also concerns about the ability of families to access the supports and services for their child/ren with a disability and their family. A community survey has provided data that confirms this is a major issue and deficit in East Gippsland. Another key concern is the lack of available supports and services for families. An innovative, locally driven approach is needed to address this issue.



On top of issues already identified, East Gippsland has experienced devastating bushfires and families are now contending with the COVID-19 restrictions (including school closures and learning from home). Given the additional stressors that have been placed on families, this proposal for a Community Connection Role has even greater urgency. Given the significant changes with COVID-19, additional feedback was sought from families. The following challenges encountered due to COVID-19 have been highlighted by service providers and parents via a combination of feedback and an online survey that Save the Children conducted:



- How anxious families are at the thought of being in social isolation with their children with additional needs without much hope of respite with services shutting down.
- Concerns about children's developmental regression and lack of support and social isolation for the child/ren and family.
- Many families don't have a licence or access to a vehicle, therefore access to services, support and basic living supplies, like food, is an issue.
- Families acknowledged the positive overall impact of the 1700 activity packs distributed across East Gippsland, funded and supported by Uniting and Save the Children. This is an example of innovation. Being flexible and responsive to families is important. A few families thought the idea of activity packs being available for their children was a good idea.
- With the changing environment, access to the internet, devices and network access is needed.
- It seems a few families have had their NDIS plans funding slashed so this has been an extra stress on top of the bushfires and COVID-19.





A gap that has been identified is the lack of opportunity (or capacity) to **inform, support** and **walk alongside families** to understand the service system eligibility. In addition, there are no mechanisms to hear the needs and understand the challenges and supports required by families in a coordinated manner, and to identify challenges and opportunities and look at how changes in the system could occur. The CWANWG is urgently requesting support for this proposal to address the identified deficits as outlined above.

In addition to the experiences of families in East Gippsland demonstrated in recent survey results, there is a clear acknowledgement that there are challenges for many families and community members in accessing supports that enable community participation. These challenges are outlined in Reeders, D., Carey, G., Malbon, E., Dickinson, H, Gilchrist, D., Duff G., Chand., S., Kavanagh, A. & Alexander, D. (2019), which highlights the problem of **'thin markets'**.

Thin markets describe where there are deficiencies in the market, which could include a low number or a lack of service providers or a complete gap (or market failure). There are also other considerations raised by Reeders et al., (2019), which include key considerations of market sufficiency and market diversity. These terms are important when thinking about the challenges faced in East Gippsland.

Market sufficiency refers to whether needs can be met by the market. Secondly, market diversity is where there are a number of service providers in existence, so that choice is an option. There are a high number of communities where market diversity is not present and families don't have a choice.



The Children with Additional Needs Working Group has conducted two surveys in East Gippsland—one around their experiences of accessing respite and family needs in this area and the other on NDIS experiences. A summary of the results of both the surveys are below.

The following provides an overview of the key results from the survey that sought to understand the experiences and needs of families in regard to respite services and options.



East Gippsland Respite Survey:

There were a total of 35 respondents, assessing the support available to/utilised by families. There are a number of key results that were identified from the survey, as outlined below:

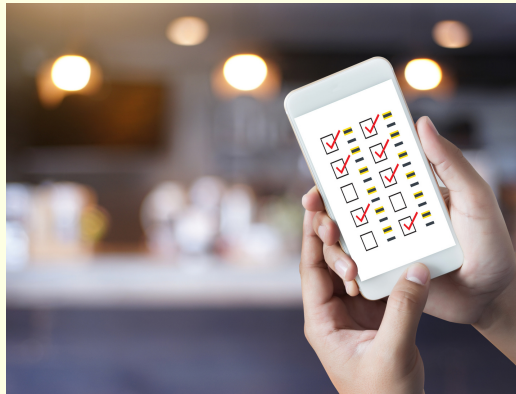
- ✓ It is the children of the family surveyed that require support (68%) with typically, male (78%) children, aged 7—12 years (44%).
- ✓ Adults requiring support only accounted for 22% of respondents.
- ✓ Autism Spectrum Disorder (ASD) is by far the most common disability stated.
- ✓ Overwhelmingly, families are not getting the information support or services they require for themselves and their child/ren with a disability (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 and parents' retreat are among the popular ideas.
- ✓ In terms of regularity, fortnightly assistance (66%) and during school holidays (53%) were commonly required for social and community participation.



"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 one service and the only service is available through another organisation. 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."

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%).



NDIS experiences in East Gippsland:

A second survey regarding NDIS experiences in East Gippsland was developed due to the concerns that were raised by a number of community members and services about access to the NDIS and services identified in NDIS plans. It is important to acknowledge that the NDIS seeks its own feedback with participants/carers on their experience with the planner at a Planning Meeting and not when the participants have received their plans. The NDIS does not follow up with how the participant/carers find their experience once their plan has been finalised. This survey was an attempt to understand participants/family experiences once a NDIS plan had been received. The survey was completed by 23 people and highlighted that:

- ✓ 69% of respondents stated that their access to NDIS was Poor, Moderately Poor or Average
- ✓ 59% of respondents stated they were not able to access the services identified in their NDIS plan



"To sum it up concisely but without window dressing –it—the access to NDIS is total and complete s###. There are no providers for support work. I had to set up a business in order to employ people to do –this—a lot of work! There are few therapists and none willing to work with complex clients. We have literally had EVERY SINGLE speech therapist from Bairnsdale to Sale to Traralgon either be too busy to help or more commonly, refuse on the basis my children were too complex. We moved here from another area where we had good Clinical psych, Speech therapist and OT and have now been without any help for ages. It is breaking the family"



The feedback received from families from these two surveys clearly indicates that there needs to be more support in East Gippsland in accessing the information, supports and services via the NDIS and the broader service system. There is also a need to ensure there is broader, sustainable change as a result of strategic thinking and exploring innovative ways in which service gaps can be filled. There is also a need for building capacity and education across the system, both from a service provider and family perspective. A greater understanding is required across all services about the experiences and needs of families, children and young people. There is also scope to increase the capacity of families and their children to navigate processes in order to expand the level of supports and services they can access. There is a deficit in support for families prior to identifying a plan through a planner. Additional information about pre-planning would benefit many families. Streamlining processes for families and developing ways in which one support coordination role is available for multiple children has also been an opportunity that has been identified.

The issues that have been highlighted in the survey responses, together with anecdotal evidence gathered by service providers and from families themselves, identify a critical need for extra resources to be funded to assist with providing pathways between service providers, NDIS and participants in East Gippsland.

This proposal recommends employing an independent role to provide practical support in the navigation of the LINK/NDIS eligibility pathways and map service provider protocols in East Gippsland.

A VCOSS report (VCOSS, 2017), highlighted a role like the Community Connection position would be needed in rural and remote areas, as service provision can be hard to access and difficult to navigate given fewer service providers are available and conflict of interests may occur.

The Community Connection Role would identify local opportunities and supports for children and their families not eligible for the NDIS, as there is a fear that those not eligible for funding may miss out on services all together. This role would also assist families who are disengaged with the NDIS—particularly Aboriginal and Torres Strait Islander individuals to re-engage with the system. The impact on the child of not getting timely and appropriate support affects the child's developmental trajectory and life opportunities and the sustainability of care for families.



The Role will:

- ✓ Work alongside families to build capacity and help navigate the disjointed service system.
- ✓ Map and document pathways for children and their families in ways that are easy to understand.
- ✓ Work with disengaged families to maximise opportunities to re-engage with the NDIS.
- ✓ Develop innovative responses at an individual and systematic level to achieve a more responsive system that meets the needs of children and their families.
- ✓ Provide, through the CWANWG, networking activities and build partnerships with other service providers with a view to promoting the rights of families to gain access to services.
- ✓ Respite has been identified as an urgent need for families. Supports for families in identifying local options and opportunities for innovation and sustainability to address their respite needs.
- ✓ Work with key stakeholders to fill service gaps in creative ways or develop mechanisms to encourage service providers to deliver services in gap areas.
- ✓ Explore innovative models of service delivery for small, remote areas of East Gippsland.



The CWANWG is requesting funding of **\$120,000** for 1 EFT **annually** (including on-costs and transport) for a period of **three years** to ensure sustainable and long-term outcomes are achieved. Evidence of the impact of this position will be collected and funding an evaluation of the position at a cost of **\$25,000** will also be sought.

The Gippsland Disability Advocacy Incorporated (GDAI) has agreed to be an independent auspice and will host the role when funded and ensure the role remains independent.

The CWANWG is now seeking a commitment of funding for this clearly identified role for the East Gippsland Community.



References

- Reeders, D., Carey, G., Malbon, E., Dickinson, H, Gilchrist, D., Duff G., Chand., S., Kavanagh, A. & Alexander, D. (2019). Market Capacity Framework. Centre for Social Impact:Sydney.
- Victorian Council of Social Services (VCOSS), A smooth NDIS transition, VCOSS Submission to NDIS Joint Standing Committee inquiry into Transitional Arrangements for the NDIS, August 2017.