Recovery & Resilience Building for Children with Additional Needs and their families - Final Report

Australian Government

VICTORIA State Government

Gippsland Disability Advocacy

Children With Additional Needs Working Group

Acknowledgements

Acknowledgement of Country

The members of the Children with Additional Needs Working Group would like to acknowledge the First Custodians of the land, the Gunaikurnai people and the Monero and Bidawel people in the far East, of the land that encompasses East Gippsland Shire and on which we work and play. We deeply acknowledge their ongoing connection to culture and country and acknowledge that their land was never ceded.

Other acknowledgements

We would like to thank the members of the Children with Additional Needs Working group (CWANWG) who have given their time and experiences to make the report what it is today. These members showed up every month, had great input and shared their experiences. It has made the report richer for the information.

Our heartfelt thanks also goes to the many families/carers who have been so generous with their time and shared their stories. We continue our commitment to work beside you to help ensure our children and young people continue to receive the best care they can.

Thanks also to organisations and private service providers for sharing their insights into a period of time which we have never experienced and we can all learn from.

Lastly, a big thank you to Bushfire Recovery Victoria who provided resources to make this project happen. Please know it has made a difference to many families and carers of children with additional needs. Many enjoyed an independent platform to have their voices heard. Thank you.

This report was developed by Jodie Simpson - The Project Lead from Jodie Simpson Consulting with support from CWANWG members, Rachel Bell (Yoowinna Wurnalong Aboriginal Healing Service), Adrian Terranova/Monica Pound (Gippsland Disability Advocacy) and Ruth Churchill/Kirsten Van Diggele (Uniting VicTas). Thanks also to other members of the CWANWG who have provided their feedback and help with keeping the project on track!

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Executive Summary

The Bushfire Recovery and Resilience Project (BRRP) was developed by the East Gippsland Children with Additional Needs Working Group (CWANWG) to gain an improved understanding of the experiences of families and carers who cared for children with additional needs through the Black Summer Fires and into recovery, including COVID.

Auspiced by Gippsland Disability Advocacy, the work was realised through funding provided by Bushfire Recovery Victoria – Local Economic Recovery Round 1.

The purpose of this report is to use it as a tool to learn from and ensure key learnings are captured and reflections are embedded in future planning and policy decisions.

The BRRP worked alongside families, carers, service providers and organisations to share the challenges they experienced and identified opportunities for supports that will make a difference for future emergencies. With a key focus on building the capacity of parents/carers of children with additional needs across East Gippsland, mapping and documenting pathways for children/families in ways that are easy to understand and improving feedback from children/families to improve support services, the BRRP has received genuine engagement, providing a unique insight into how to improve systems to achieve better outcomes for families/carers and children.

Throughout the life of the BRRP (May 2021 – July 2022), over 350 engagement sessions with families/providers/organisations were held, identifying key themes:

- **Fire and Recovery:** A range of experiences occurred during the fires and throughout recovery. The decision to stay and defend or evacuate varied greatly and trauma was experienced both at home and at relief centres. Families also experienced mixed supports and services through and immediately after the event. Overall supports were not well equipped for disability needs.
- Other insights included communication used by emergency managers which caused confusion for families. There was also a lack of trauma services and recovery activities to assist children with additional needs. Children and families alike felt anxiety caused by planned burning. Distribution of funding for recovery supports and building capacity of emergency responders has been identified as a priority.

- **COVID-19:** Parents/carers reported an increased anxiety levels in children with additional needs with many children and families experiencing limited or no supports due to lack of access to therapy. This was also experienced by service providers and organisations not being able to directly access families and children. The introduction of COVID vaccinations in January 2022 for children also caused concern in East Gippsland.

- The need for understanding the **National Disability Insurance Scheme (NDIS)** and how to make NDIS Plans work flexibly for families during fires and through COVID.

- Local support services continue to be limited and have long wait times for children to access, including the understanding of which pathways families and carers can use to have their **child/ren diagnosed** if there are concerns about delays.

- Adjustments to ensure children **returning to school** were supported and families/carers were aware of questions to ask to assist with transitions.

To provide **immediate support** to families the following actions were implemented in the project:

- An East Gippsland Service Provider list was developed and shared through local services across East Gippsland and will be placed on the “information hub” to ensure version control can be maintained.

- An online information hub has been commissioned.

- More than 400 Person-Centred Emergency Planning (PCEP) booklets were distributed across East Gippsland through the BRRP and collaboration with the Department of Environment, Land, Water and Planning employees. Four service providers have agreed to continue to work with families to help with emergency preparedness as a part of their sessions. The PCEP aims to support people with diverse needs to think about what they can do in an emergency.

- A trauma informed, inclusive event was held for children with additional needs at Christmas (Sensitive Santa) with 18 families participating in person and online.

- Social stories for planned burning and COVID vaccinations were developed and distributed to children and families through the East Gippsland network of over 850 contacts throughout the region including bush nurses, schools and early years centres as well as organisations and service providers.

- Two families were supported to share their stories at the Royal Disability Commission.

- One Stop School Shop guidelines were developed to assist parents with ensuring adequate supports (reasonable adjustments) are made for children with additional needs returning to school.

- An Emergency Management Reform Project Paper was developed to address the critical priority areas for future work including accommodation, Vulnerable Persons Register and Relief Centres as examples.

- An analysis of the use of Media and Communications to share relevant information to families that meets their needs, based on family feedback.

- The next phase for the BRRP includes working with communities, decision makers and organisations to provide pathways for the ‘lessons learned’. This next phase will enable inclusive practice to be embedded into future planning for emergency response. Other key areas of the project going forward will be to bring more emphasis on the National Disability Insurance Scheme; understand and promote diagnostic pathways in and outside East Gippsland and school readiness for children with additional needs. All of these areas have been identified by families as significant areas of priority going forward.

- The families, carers and service providers/organisations who provided their input to the project are deeply acknowledged. Without their support and their courage to share their experiences, the BRRP would have never provided the rich insights that this report has captured.

Message From Our Leaders

We are thrilled to introduce this Final Report which has been developed after a culmination of over 14 months of work within the East Gippsland community. With a key focus on building the capacity of parents/carers of children with additional needs across East Gippsland, mapping and documenting pathways for children/families in ways that are easy to understand; and improving feedback from children/families to improve support services, this report provides the basis of future work. The hard work has been done. We know what we need to do to help families and carers of additional needs in times of emergencies.

We are extremely proud to have been involved in a very unique project - to hear the voices and experiences of those families and carers of children who have additional needs as they experienced the Black Summer fires and moved into a COVID restrained environment.

With a number of key opportunities that families themselves have considered and shared, its now up to all of us to make a difference. We all have a role to play and we say a huge thankyou to everyone involved and everyone who shared their story. These lived experiences are vital for learning and improvements.

We cannot wait to see how the information collected continues to play a significant role in helping children, families and carers into the future.

Kirsten Van Diggele
Chair- Children with
Additional Needs
Working Group

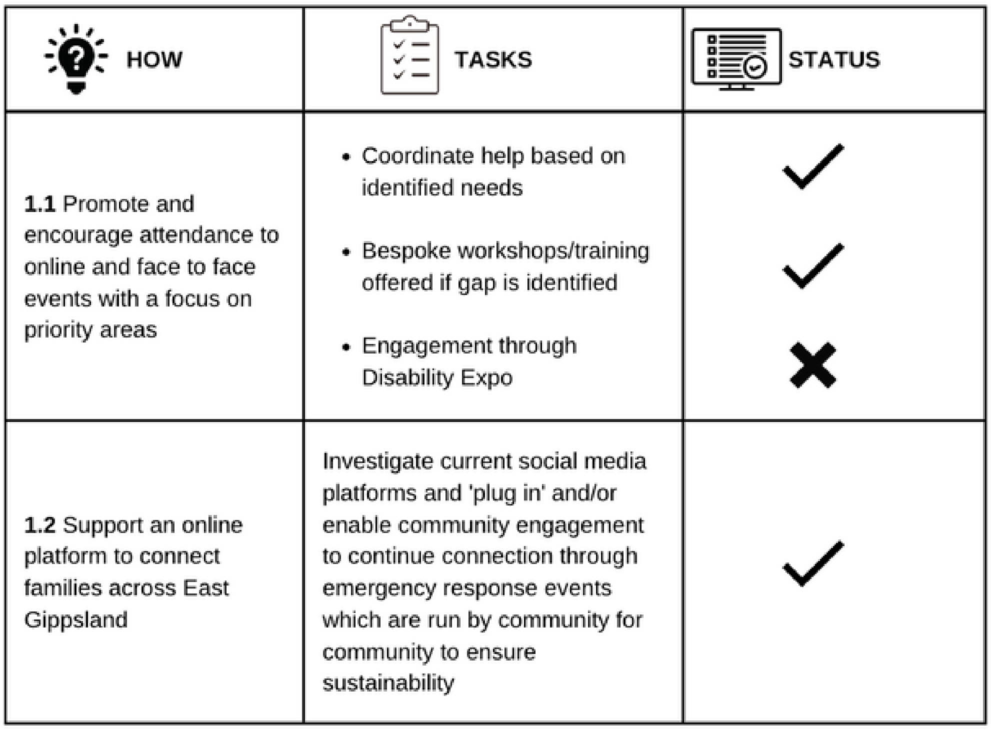
Monica Pound
EO - Gippsland
Disability Advocacy

This work needs genuine engagement from agencies/services involved in emergency management. The impacts of the bushfires and COVID demands us to listen to communities and have a willingness to actively deliver on what is being told by families and service providers. This is our opportunity to understand our obligations to follow through so we can be prepared for future emergencies - particularly for families with children who have additional needs.

How to read this report

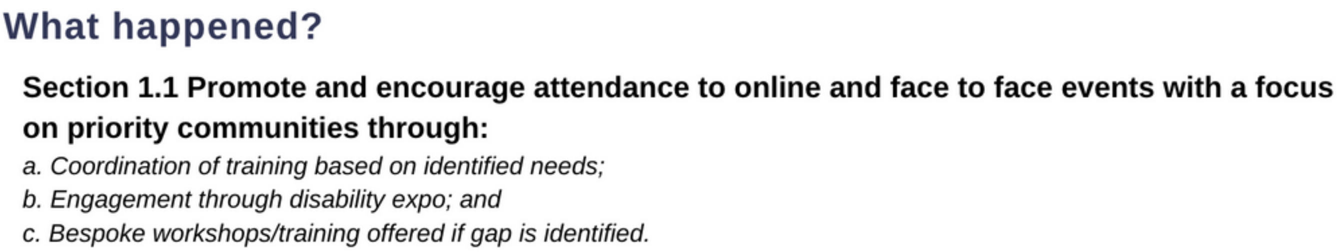
The Bushfire Recovery & Resilience Project (BRRP) has been a combination of many smaller projects and key outputs. This report has been developed around those key projects and broken down into the following areas for ease of reading (as an example, Objective, What did we do? and What did we learn? and Reflections):

Objective:
Objective 1: Build the capacity of parents/carers of children with additional needs across East Gippsland



HOW	TASKS	STATUS
1.1 Promote and encourage attendance to online and face to face events with a focus on priority areas	• Coordinate help based on identified needs • Bespoke workshops/training offered if gap is identified • Engagement through Disability Expo	✓ ✓ ✗
1.2 Support an online platform to connect families across East Gippsland	Investigate current social media platforms and 'plug in' and/or enable community engagement to continue connection through emergency response events which are run by community for community to ensure sustainability	✓

Subsections (the "how" and "what" - tasks)
Promote and encourage attendance to online and face to face events with a focus on priority community hubs, for example:



What happened?

Section 1.1 Promote and encourage attendance to online and face to face events with a focus on priority communities through:

a. Coordination of training based on identified needs;
b. Engagement through disability expo; and
c. Bespoke workshops/training offered if gap is identified.

What did we learn and reflections
This section is used to reflect on the lessons learned and reflections - tying back to the Objectives.

What did we learn

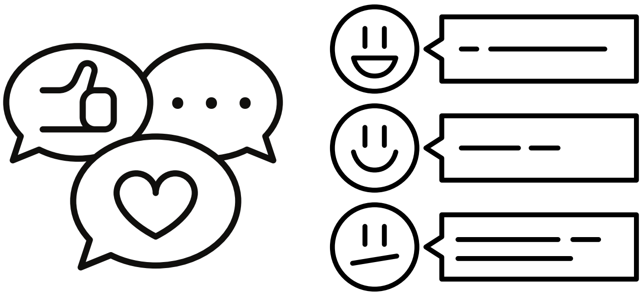
Reflections

Why this project?

The Children with Additional Needs Working Group (CWANWG) is a sub-group of the Children's Wellbeing Collective (CWC), a partnership of agencies overseeing the East Gippsland Early Years Plan and the Children's Wellbeing Initiative. The Children's Wellbeing Initiative emerged to support community responses to the data highlighted in the Wellbeing of Children and Young People Report (2014 and 2018) developed by Save the Children. The CWC receives recommendations from the CWANWG, which identifies issues for children with additional needs and their families and how improvements can be made. The CWANWG meets monthly and has been successful in giving families and services a platform for a variety of issues. In the wake of the Black Summer Fires, it was clear to the CWANWG that seeking to understand the challenges and future opportunities was of critical importance to help with recovery efforts.

The CWANWG was successful in receiving funding through a Bushfire Recovery Victoria Local Economic Recovery (Round 1) grant in January 2021 with three main objectives of the Bushfire Recovery and Resilience Project being:

- Building the capacity of parents/carers of children with additional needs across East Gippsland
- Mapping and documenting pathways for children/families in ways that are easy to understand
- Improve feedback from children and families to improve support services



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 with the overarching outcome of:

Children with additional needs get what they need to support their development.

Key Achievements

There have been many achievements and highlights over the duration of the project.

Over 350 meetings with families, providers and stakeholders held to hear voices across East Gippsland

Sensitive Santa sessions held as a a recovery activity in person (12 families) and online (6 families)

Strategic relationships created and enhanced

10 stories collected from families. Two families signposted to the Disability Royal Commission

Evaluation reports written for Sensitive Santa, NDIS 101 Sessions, Media and Communications Analysis and reports developed for the Emergency Management Reform Project

14 surveys of service providers and organisations

Two support groups created for families/carers in Mallacoota and Orbost

Connections made with our First Nations community throughout East Gippsland

Online presence to connect and home important reports and resources

Signpost to 22 webinars/workshops with a reach of 37,000 and online activities to grow family/carer capacity

Over 400 Person-Centered Emergency Planning Booklets distributed across East Gippsland

One Stop School Shop - a guide for parents seeking supports (reasonable adjustments), as children transition back into school

Ad hoc/bespoke training in Bairnsdale, Buchan, Orbost and Mallacoota provided for better understanding the National Disability Insurance Scheme

Two social stories developed: Planned Burning and COVID Vaccinations- circulated throughout East Gippsland

Support worker model co-designed and developed with Mallacoota community

Objective 1: Building the capacity of parents/carers of children with additional needs across East Gippsland

What did we commit to?

HOW	TASKS	STATUS
1.1 Promote and encourage attendance to online and face to face events with a focus on priority areas	• Coordinate help based on identified needs • Bespoke workshops/training offered if gap is identified • Engagement through Disability Expo	✓ ✓ ✗
1.2 Support an online platform to connect families across East Gippsland	Investigate current social media platforms and 'plug in' and/or enable community engagement to continue connection through emergency response events which are run by community for community to ensure sustainability	✓

> *"We need recovery information to come through now. Now is the time for checking in with families (June 2022). Ask "what's surfacing for you now?". Provide opportunities for webinars, record something so that families can watch in their own time. Mental health for children with additional needs. Ideas of things to do that can help."*
>
> *Mum from East Gippsland*

What did we do and what did we learn?

What did we do?

Section 1.1 Promote and encourage attendance to online and face to face events with a focus on priority communities through:

a. Coordination of training based on identified needs;
b. Engagement through disability expo; and
c. Bespoke workshops/training offered if gap is identified.

a. **Coordination of training based on identified needs:**

An important part of promoting and encouraging families/carers to attend workshops and online webinars was to understand needs and future opportunities. Information collected was through face to face meetings and workshops (between COVID lockdowns).

Predominately, families and carers identified 4 key themes requiring help and further support:

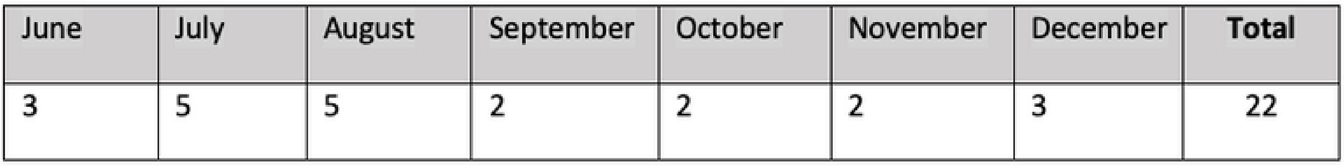
1. Fire recovery
2. Transitions back into school and understanding of supports for students (reasonable adjustments)
3. Understanding key pathways for diagnosis
4. NDIS - including access, planning and implementation

A Memorandum of Understanding (MOU) was developed between Gippsland Disability Advocacy and Association for Children with Disabilities (ACD) in June 2021 to enable workshops and feedback, with a number of questions added which were East Gippsland specific to ensure we were able to measure the impact of families attending and how carers/families were sourcing their information. This was an important step as much of the ACD information was relevant to many families, particularly regarding transitions back into the **school environment and NDIS** and was offered free of charge. Due to COVID lockdowns, much of the information became available online and more accessible for many families, however anecdotal feedback suggests that while interested, families were unable to join online due to network/internet issues. The closest representative from ACD is located in the Latrobe Valley, so face to face sessions were also difficult as employees were unable to travel far in to the East Gippsland Region.

From the period of May 2021 until February 2022, a concerted effort was made by the Project Lead to promote as many sessions to build parental capacity in many areas of interest and opportunities that were identified through parent/carer feedback. Table 1 provides information on the number of opportunities shared and Table 2 identifies the online social media forums that were used throughout East Gippsland.

The likelihood of local families using state or national websites or facebook pages for information about local events would need to be further investigated. If the assumption is that courses/webinars/workshops, etc. are being run and people are engaging with the content on the state and national pages it would be advantageous to undertake further work to engage families for their content and support, especially through fires.

Table 1 : Month & Number of workshops/interests shared 2021



June	July	August	September	October	November	December	**Total**
3	5	5	2	2	2	3	22

Table 2 – social media Page and Membership Numbers (audience reach)

Social Media Page Name	Membership #'s
Lakes Entrance Chatterbox	6.8K
Orbost Chatterbox	3.8K
Bairnsdale Chatterbox	2.1K
NDIS in Gippsland	776
Mallacoota Community News	10.3K
Special/Additional Needs Parent and Carers Support Group	144
Bairnsdale Mums	1.9K
Lakes Entrance Noticeboard	11.4K
Mytime/Play connect - Bairnsdale	120
Total	**37,340**

Information shared included (but not limited to):

- Sensitive Santa
- Protective Behaviours training
- Early Years Autism workshops (face to face and online workshops)
- Association for Children with a Disability online workshops
- NDIS 101 Bespoke Training (Mallacoota)
- Journey of Hope
- Gippsland Disability Advocacy Carers Days
- Gippsport Golf Day for children with a disability (Bairnsdale)

Table 3 depicts a sample of organisations which have a presence in the East Gippsland Community and where they are based (National, State or Local).

Table 3 – Organisational pages that have touchpoints into East Gippsland Community

Social media Page Name	Membership #'s
Uniting Vic/Tas (State)	5.5K
Save the Children (National)	166K
Playconnect (Victoria)	64
Gippsland Lakes Complete Health (Local)	2.7K

Anecdotal evidence (from organisers of workshops) suggests that the uptake of attendance was up between 25-75% due to social media presence on local pages.

Overwhelmingly, the biggest success was Sensitive Santa where most of the participants saw the flier on the social media pages across East Gippsland.

Depending on the amount of information to share, it could take up to 1.5hrs to post across the nine social media pages per month. If the CWANWG is going to sustain this option, acknowledgment of the time it takes is important. Identification of one or two people within the CWANWG (preferably a paid position) to send information too will be beneficial.

The sharing of information on social media pages has been beneficial to families who source a lot of their information from this platform, particularly if it is community focussed. It has also had the added benefit of continuing a community conversation about children with additional needs and their families, being supported in a more open manner in each community. Comments have been received “what a great idea” and then tagging families has been an unexpected but positive outcome allowing us to reach families who the CWANWG may have not had previous connection with. As an example, the sharing of Sensitive Santa on at least 9 East Gippsland social media pages meant that all 15 places (face to face) were filled and a further 6 were available for online sessions across East Gippsland. These are families we may have not met if this platform was unavailable.

Reliance on the ongoing existing relationships within community is important to ensure information that is distributed through email reaches the intended audience. Having contacts lists (with permission and centralised) would be helpful to ensure continuity of help and assistance with families in case individuals leave their roles in the organisation.

A small number of families prefer text, newsletters and emails over social media (facebook). During the BRRBP, efforts to be inclusive of those preferences did take extra time to ensure the same information was being shared to everyone. While no ‘official’ contact list has been formed to continue integration with families who have come forward as a part of the project, some interest in continuing with the work undertaken by the CWANWG has become strong, especially in those areas not traditionally serviced by the CWANWG members, including far East Gippsland. Many families had not heard about the CWANWG, or it's work so there has been major benefits to increase the profile of the work being done by the CWANWG and the types of things that can help families going forward. An ‘information hub’ to share what has been collected and developed because of the feedback would be an excellent opportunity for ongoing assistance to families who are unable to make it to meetings.

There are several resources that have been shared to date including the Person-Centered Emergency Planning document and more recently, the CFA Carers’ Planning Guide through verbal communication. Many families are unaware of the existence of the documents and to have these centralised in one spot (or reference to where it can be found) would be of great benefit, particularly as communities continue the conversation about emergency preparedness.

One media release (shared through newspapers and local community newsletters) was distributed and introduced the launch of the project and how to access the Service Provider list. Families engaged through the BRRP have indicated that they are aware of the Service Provider list and either had a copy, or requested a copy be sent to them via email.

Face to face meetings were the most popular across East Gippsland. Many meetings were held (over 300) in 6 months with families, organisations and not for profits who had interactions within community. For families, many have been reluctant to share their own stories more broadly with others within a group environment. While this meant more time meeting one on one, the level of interactions where much more positive with more information gathered out of the engagement.

b. Engagement through disability expo

The Disability Expo Working Group (a sub-group of the CWANWG) to discuss, plan and hold a Disability Expo. Due to run in November 2021, the Working Group felt that the COVID rules and regulations were proving to be too unpredictable and made the decision to postpone until the COVID environment settled.

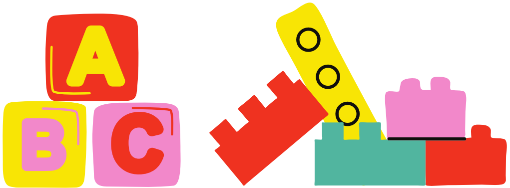
c. Bespoke workshops/training offered if gap is identified

NDIS 101 workshops were run in Buchan, Mallacoota, Bairnsdale and Orbost. There was good interest in these communities and hope is to continue to build knowledge and understanding of the many facets of the NDIS as they continue to change. An evaluation was undertaken and is listed in the "Further Reading" section of this report which contains more information.

What did we learn?

Reflections:

- Intermittent internet in very remote places prevented some families from attending. Preference was face to face workshops however was unavailable from bigger Organisations travelling to areas east of Orbost to the border, even though there was an identified need
- Helping other organisations run training in East Gippsland was difficult at times due to the inability of being able to see evaluations which could tell us if there was an increase in participation by East Gippsland families and carers. Anecdotally, Early Years Autism Workshops and Protective Behaviours Training saw an increase due to advertising in social media by the Project Lead however it was unqualified as Organisations were reluctant to ask where participants were from and how they found the information to join.
- Organisations are equipped in their policies to share information on community social media pages to reach wider audiences being distributed through the BRRBP. Overwhelmingly, families and providers look to social pages like chatterbox or carers pages instead of individual organisation pages unless the families have a direct affiliation with them. Members of the CWANWG can continue the current approach as an interim measure, however it will require an ongoing presence and commitment. Suggest nomination of several paid representatives to continue with the sharing of content across social media.
- An online information hub needs to be created because of the concentrated work undertaken by the BRRBP in the form of a website which 'connects' families to what may be happening in their community in addition to continuation of a social media presence. The information hub can house information currently developed by the CWANWG including the Education One Stop Shop and Service Provider List as examples. It is important that these documents (and others including governance documents, agenda's, minutes, and emergency resources) can also be housed and made available to families at any time. Undertaking this will create a sustainable and cost-efficient model to keeping families informed of what is happening in their community at any given time. It will also ensure documents can be 'version controlled' as information is updated at least quarterly. As one family remarked "while the Service Provider list is an excellent document, I cannot trust that the version I have is the most up to date". Information and linkages to websites like the CFA for preparedness planning would also be of great benefit.
  In times of emergency, the information hub can hold the most up to date and important information for families (signposting to Carers Gateway/Carers Victoria, NDIS and other pathways for support).
- Having a centralised administration team who can access contact lists would be beneficial to ensure continuity of service in case individuals leave organisations.
- Creation of a contact list to capture families as a part of the BRRP and ensure they have inclusive access to all events and outcomes because of the BRRBP. Permission of the families to have their data collected and shared will need to be obtained.



Sustainability Success - a member of the CWANWG (Noah's Ark) has agreed to continue connecting community with opportunities through community social medi platforms

What did we learn?

- Meetings with families to be led by families. Where there is a need (and when families are ready), the formation of a facilitated group should be supported (examples Mallacoota My time and Orbost Carer Group) have been created as a direct result of the work of the BRRBP and can be used to implement planning sessions for Emergency response and preparedness conversations.
- Investigation of a newsletter connecting all events – The CWANWG can then create a pathway for a newsletter to be shared more broadly to families and community members and keeps information on the 'information hub'.

Reflections

- COVID has been very interuptive on a number of levels including the Disability Expo. Moving forward with confidence to plan an event (and have attendees participate) will be determined on current rules/regulations around COVID
- Strategic Relationship Mapping undertaken by CWANWG. Service Providers local to the community who have social media pages may also be used to share important information (emergency related, workshops etc) to help with information distribution to families who the CWANWG may not pick up through normal channels.

What did we do?

Section 1.2: Support an online platform to connect families across East Gippsland by:

Investigating current social media platforms and 'plug in' and/or enable community engagement to continue connection through emergency response events which are run by community for community to ensure sustainability.

As per Section 1.1, the needs of the community were ascertained through face to face and workshop discussions. A notable outcome here was that many families accessed social media and local community newsletters/newspapers to source their information and rarely used larger organisational social media pages, particularly if they were not local as the content was not necessarily important/relevant to the carers/families.

Please refer to Section 1.1 for insights provided from the Media and Communications Analysis which was also used to inform this output. The need of continuing connection with families on behalf of the CWANWG was highlighted and supported by one member from Noah's Ark who has agreed to circulate opportunities to families across East Gippsland. The feed in channels are through members sharing their organisation's workshops/webinars and sessions which are then promoted on local social media (as per Table 2 in Section 1).

Work was also undertaken with the Children's Wellbeing Collective (CWC) which is a collaboration of community organisations, Local and State Government to promote the needs of children and youth in East Gippsland. The CWC have 5 priority areas of which the Children with Additional Needs Working Group is one.

A Briefing Note was developed highlighting the need of an "Information Hub" to be created at a CWC level and could be used as a depository of resources and information, including resources created as a result of this project. While the CWC are still in deliberations, there has been an agreement between Uniting and Save the Children to re-focus resources and funding to build a CWANWG online page and a complimentary Facebook page to showcase information from the project and share other resources so families can access all emergency resources in one spot. It is hoped that the Information Hub is ready to be shared by July 2022 where this and other complimentary documentation are available for community use.

As an interim measure, all emergency resources can be found on the ConnectWell website, including educational and recovery resources including reference to Birdie and the Fire, the Person-Centered Emergency Planning Workbook and the Planned Burning Social Story. The link to the website can be found here: https://www.connect-well.com.au

What did we learn?

Reflections

- Working across a large membership (CWC) to gain consensus for an online resource takes strong collaboration, commitment and leadership from key decision makers to ensure the needs of the community are considered and met. As this report is being completed, no consensus for a CWC online resource has been committed to as yet despite numerous efforts.

- While the investigation of an online platform has been met, the actual implementation (outside of scope for this project) has been slow and held up with organisational policy and procedures. Freedom to cater for the community needs should be considered as the priority rather than a 'silo' approach.

- An online platform for the CWANWG while in principle support has been received, commitment from lead members has still not occurred despite very minimal outlay for the design of the website and annual fee.

Supporting evidence for Objective 1:

- Media and Communications Analysis
- Briefing Note to Children's Wellbeing Collective (CWC) proposal to create online 'Information Hub'
- ConnectWell website where Planned Burning Social Story is housed
- Minutes of CWANWG meetings (from May 2021 - July 2022)
- Monthly dashboard of Project (from May 2021 - July 2022)
- MOU Evaluation questions
- NDIS 101 Bespoke Training Evaluation

A case study - Who cares about nits?

Ruby has a large family, in her words “a big family” (over 6 children). Ruby lives in a town in East Gippsland and like many, had their share of experiences over the fire campaign.

Ruby and her children (excluding 1) are all on the Autism Spectrum. This means that there are different ways to help her, and her children manage their emotions, behaviours and how they function. Fires had been dancing around the area for at least 4 weeks before Ruby decided she would work with her children to get them ‘ready’ to evacuate. For Ruby, this meant that every child in her home had coaching on what to do if they needed to evacuate. They ran through these routines at least 2 weeks before the day came. Ruby took great care to roleplay and even had routines and schedules if they had to evacuate within 1 hour, 10 minutes or right away. Each child ran through what they had to do twice a day for two weeks leading up to evacuation day. They thought they were prepared.

On the day of evacuation, an emergency warning hit everyone’s phones. Shortly after that, the local fire chief had posted on social media that the community were fine and safe. Six hours later the post had been removed. Ruby messaged her sister who called her back and said “the fires are going to be worse than Black Saturday. You won’t have time. Get out now”. This member of the family had family working in agencies on the fire and she felt that they had the best knowledge and advice. Shortly after, the Emergency Warnings came through to evacuate.

Ruby made her way to the local relief centre and was advised that the town had completely closed and they were to evacuate to a relief centre in another Local Government area. “Get your kids and go”. “We will ring to check if you have left”. Ruby confirmed they did ring which she was thankful for.

This also meant that the children were provided with their 10-minute warning to put their routine/schedule in place – the one they had been practicing for twice a day for two weeks

Despite all of the coaching and practicing, understandably, the children were panicked. This resulted in one red trolley (from one child who was scared of it being burned), garbage from the bin being collected and toys. Even with rigorous visuals and schedules (to do lists), the family (who were advised to go to a relief centre hours away) left with no clothes other than those they were standing in due to the fast pace of the evacuation but all the other collected items which were of no use to the family.

One child was so affected that he kept punching himself to the head until he was barely conscious. Ruby and her partner did their absolute best to help her children cope with what was unfolding.

At one point on their journey to the relief centre, there was a point in the decision making about the best way to make it to the relief centre. It could have been through a coastal town (which came up as having a car accident on the only way out) or through an inland town which was in the line of the fire front but was not yet closed to traffic. The family made the choice to go through the inland town and by 4pm it was jet black. Hindsight indicated they should have gone the other way, but they were not sure how long traffic was backed up for to try and get through.

Ruby had an asthma attack in the car. She suffered mild asthma as a child, but since the events, has now been diagnosed and continues to live with severe asthma and has to be conscious of air quality.

The family arrived at the Relief Centre in a traumatised state. It wasn’t until they started talking with the relief centre coordinator that things became confusing for the family.

A case study - Who cares about nits?

At the relief centre, what ensued was a conversation with words to the effect of:
Coordinator: “you shouldn’t be here; you aren’t officially from a red zone, and you shouldn’t have evacuated”
Ruby: “the Government through their app told me to leave and we will continue to be in a red zone in the morning as well”
After more conversations, the coordinator allowed them to stay overnight.

As the family worked out that the children had packed toys and rubbish, they were also concerned at the large number of people staying in the relief centre and the need to keep their children safe. Ruby said that she was concerned for her daughter who was 5 years old. ASD kids often have trouble identifying how to keep themselves safe. Her daughter Casey* was prone to talking with males and with many children, Ruby could not feel confident that she could keep her eye on Casey and keep her safe. At this point, there were children in an unfamiliar environment, missing any regulation tools and supports they would usually have to keep them regulated. The family decided to stay in a local motel to keep the children safe and together. “The motel we stayed in was nothing short of amazing. They allowed us to bring our cat in and they also put on bbq’s for us”.

Once this was sorted, Ruby said she received a phone call from the relief centre coordinator who said “you are not welcome back until your daughter has been treated for head-lice. The alerts are also gone now, and you can go home. The relief centre is being closed and we are closing our doors to those who are in the orange zones. And even if the zones changed, you can’t come back until your daughter’s nits are treated”.

Ruby understandable felt incredibly embarrassed that her daughter had head-lice. She also felt very judged because her family was large, and they did not have access to clean clothes. Due to the treatment her family endured, they decided to stay in a motel where they had used up all their savings keeping safe and spending $100 on head-lice treatment for their family.

Air BnB’s at that time became free for fire evacuees and the family found themselves around 3 hours from their home. The family made the choice to stay at a BnB to save some money. After a very short stay, the family ‘felt’ the accommodation owner looked down at the family and again felt judged. “I think she regretted opening her door to us”.

The accommodation also moved them on after their short stay by saying “you need to leave because we want to open it now to families from Mallacoota who are coming this way. Your area is in orange”. Ruby knew that the movement between red and orange on the system would again make its way back to red as the fires had been circling their town for over a week. I told her there was another evacuation coming, but it didn’t seem to matter. The family reluctantly made their way back to the relief centre.

The Relief Centre coordinator continued to provide advice that was against what the family had needed. A chaplain working in the centre at the time had connected with the family and provided support for Ruby to be assessed by a doctor for her ongoing asthma as well as other comfort items. At one stage through the morning the coordinator said “we are closing our doors, you are going to need to leave now”. Ruby said “we have appointments made and we really can’t go home because the air quality is so poor, it will kill me. If I go home now with everything going on, Im going to die.” The coordinator said “we need to close.” Ruby said “if we are to leave, is it ok to grab some lunch? We have nothing”. The coordinator said “no, we are closing”.

Not long after, the Chaplain checked back in with the family. Ruby said she was distraught and said she couldn’t see the doctor anymore because she and her family were told to leave. Ruby said to the Chaplain that they had used all their money and couldn’t stay anywhere. The Chaplain advised that she support the family and that Ruby was to see a doctor before going anywhere.

A case study - Who cares about nits?

Ruby and her family spent a further five days at a local school that opened to her and her family. She said the difference in treatment between the school and the relief centre was enormous. Finally, her family had received the support she was looking for. She finally felt that she and her family were not a burden because they had additional needs. Ruby's family watched the air quality levels and at the right time returned to her community to start recovery. Ruby said that she never caught the name of the lady who helped her that day but wanted her to know the difference she made. She said she felt like royalty in her care after everything they had been through.

Ruby and her family were away from her home for a total of 15 days. Ruby felt she did everything she could to support herself and her children and their additional needs.

As recovery began, there were no case managers assigned to Ruby and her family. Her children were also not given any trauma counselling (and still haven't to date). Some of her children look to the sky and wonder if the clouds are smoke. One of her children (6) has in Ruby's words "broken". His personality changed the day we were in the local shopping centre where we had evacuated to. He fell to the floor, and he changed forever that day. He is more aggressive and lashes out. He struggles to also communicate how he is feeling. He needs help.

Reflections

*None of my children "behaved badly" at the relief centre. They did not scream or run around. They were quite calm given their circumstances, a place somewhere with high sensory overload and of course new. We were treated as a burden.

*Bonfires have triggered my children. The smell of the first woodfire burning has triggered my children. We have a lot of healing to do.

*We were recently in a hospital setting and the accommodation housing us held a fire drill. My son bolted and I had a panic attack. We were not forewarned about the drill. When I communicated with the hospital that we were from East Gippsland, there were huge apologies. They should have recognised our trauma. Again, we still have a lot of healing to do.

***In the height of bushfires, who cares about nits? We were a family seeking support and shelter. When the Coordinator said that we were not welcome until my daughter had been treated for head-lice, I was so embarrassed. I wondered who had seen them and how the conversation happened for the coordinator to know. It could have been handled so much more sensitively. We were already broken and confused. To have this conversation after what we had seen and been through, who honestly cares about nits. I felt there was so much stigma about this and the fact that my family were additional needs. It's like they didn't know how to work with us.**

A case study - Who cares about nits?

What Ruby's best experience looks like:

Small sensory packs, sensory tools that can help reduce anxiety if in a relief centre

Consistent messaging about the fires. For those who have cognitive or neurodiverse brains, the inconsistency of messaging between agencies can be very confusing. We need one line of messaging to help us. The local fire chief’s message on social media set us back as a family.

Need to have a set up where families/carers who have additional needs kids/bigger people in their care are offered a billeted property or motel. We experience many more obstacles (safety of our children because of the way they think/behave) and to have additional support around us would be welcomed.

More check ins by our service providers, those that know us the best. They can help us help our children with social stories or things that we may need in the moment. We heard from no one other than our local regional health clinic on our return to our community.

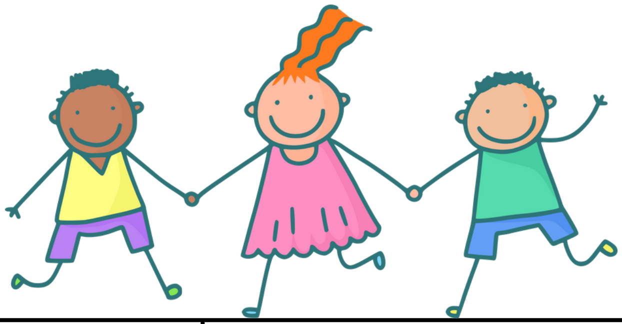
We should not be shamed because of our disability. Come to us with “how can we help and what support do you need” rather than closing down on us. It is disempowering. We felt there was so much judgement. All we needed was support.

Better supports through recovery. We would have liked the option of accessing trauma counselling for myself and my children. We feel like we have been ‘missed’. (Authors note – a referral has since been made to the local BRV People and Wellbeing Coordinator to work with the family to provide a pathway for counselling and other support that may be needed).

More understanding of financial assistance. I think we could have received more funding if my partner and I applied separately (which we saw others do and were informed later that’s what we should have done), instead we applied for DHHS funding as a family. It was not near enough. Our savings were run dry for that 15 days we were away from home and we are still trying to recover nearly 20 months on.

Objective 2: Map and document pathways for children/families in ways that are easy to understand

What did we commit to?



HOW	TASKS	STATUS
2.1 Collect and collate pathways from service providers and centralise for families across East Gippsland to explore, particularly before, during and after emergencies	• Under take a needs assessment • Create a pathways document (ECEI/NDIA) for families that use easy language	✓ ✓
2.2 Work with key groups like Amaze and VALID to promote their availability across East Gippsland	Investigate availability and their reach into regional areas like East Gippsland, including in times of emergency	✓
2.3 Develop and maintain a service provider list and update quarterly for families	Continue the monitoring and updating of service provider list and work with EGSC and GLCH for extending reach and version control	✓

"None of the services my children were receiving phoned her to see if she and her children were ok"

- Mum from East Gippsland

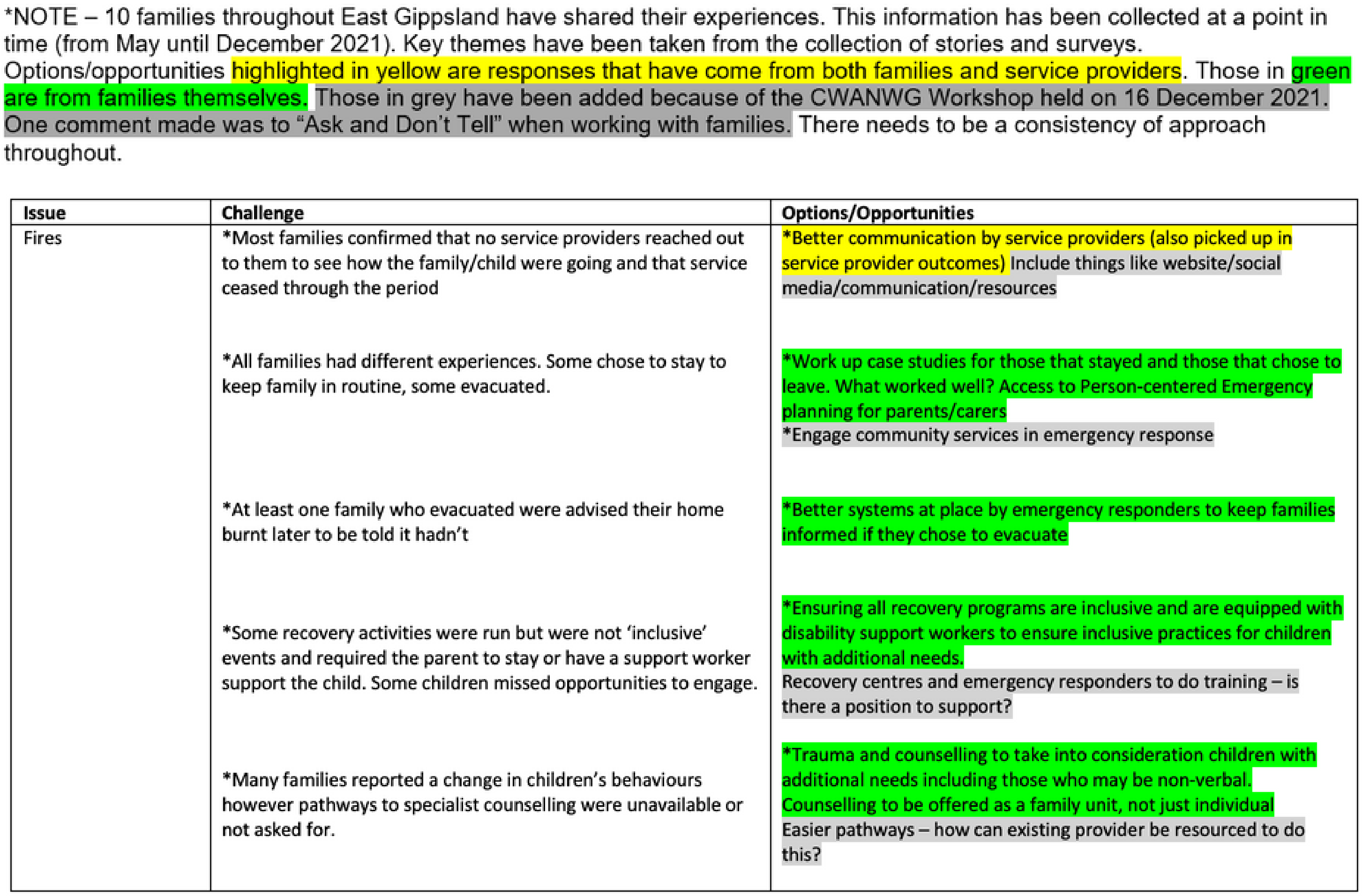
What did we do and what did we learn?

Section 2.1: Collect and collate pathways from services providers and centralise for families across East Gippsland to explore, particularly during and after emergencies through: Undertaking a needs assessment and creating a pathways document (ECEI and NDIS) for families that use easy language.

What did we do?

Data was collected throughout the project in various forms. One on one conversations, workshops, meetings and surveys of families, carers (total of 10 stories collected but meetings held with families are over 50) and service providers (14 formal surveys undertaken) provided insights into how families/carers and organisations were coping, some of the challenges experienced and some practical ways to move forward. Two tables can be found below from information that has been collected from families and carers and information collected from service providers and organisations. Quotes and additional information has also been added to enhance experiences. Case studies/narratives were also collected and have been included throughout this document. It is important to note that information has been de-identified and themed for East Gippsland. It is also important to note that this report looks at recovery 'holistically' for example there were no limitations to what recovery looks like. If families have challenges regarding the National Disability Insurance Scheme through their recovery, this has been added.

Table 4 - Insights from families and carers

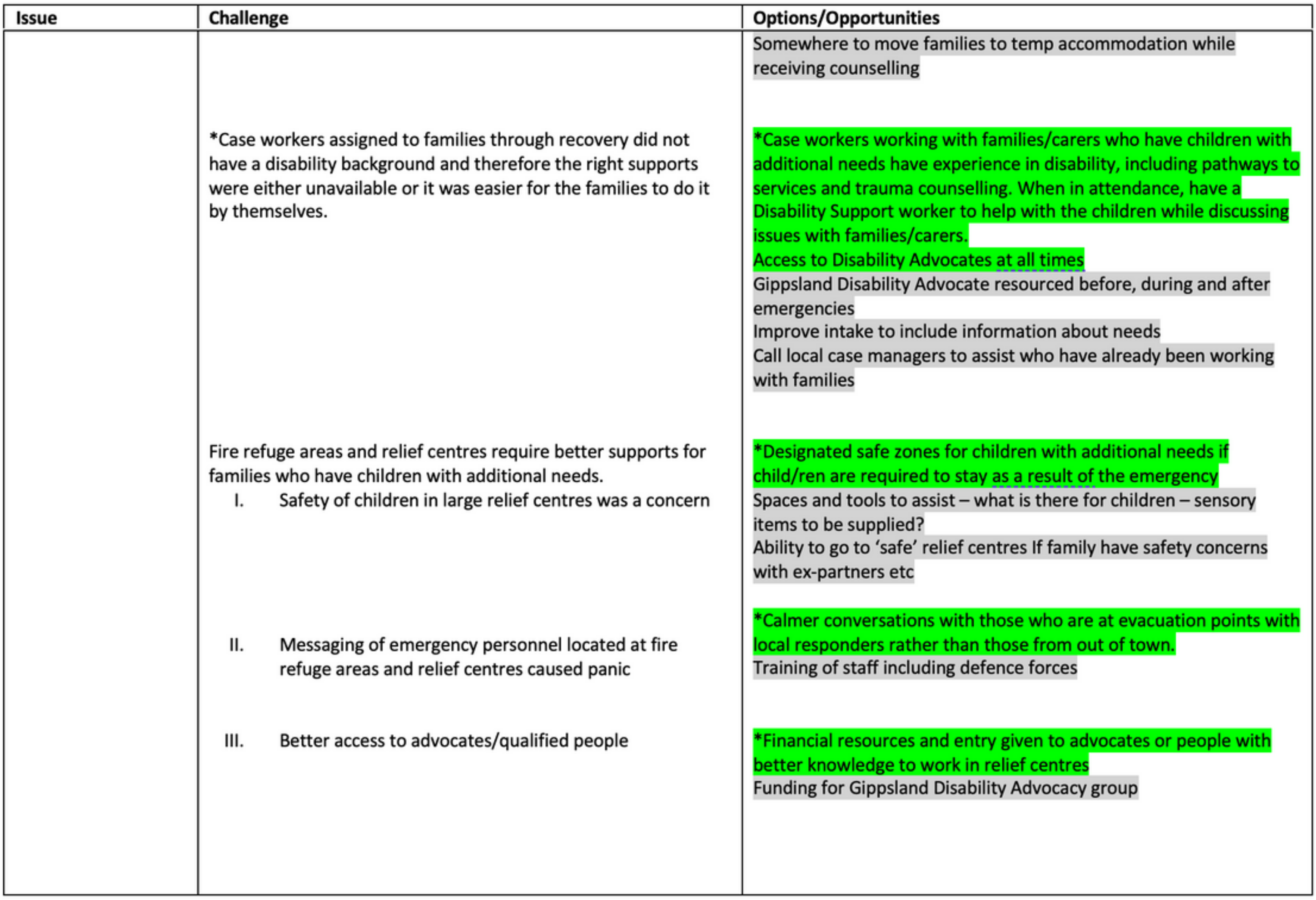


*NOTE – 10 families throughout East Gippsland have shared their experiences. This information has been collected at a point in time (from May until December 2021). Key themes have been taken from the collection of stories and surveys. Options/opportunities highlighted in yellow are responses that have come from both families and service providers. Those in green are from families themselves. Those in grey have been added because of the CWANWG Workshop held on 16 December 2021. One comment made was to “Ask and Don’t Tell” when working with families. There needs to be a consistency of approach throughout.

Issue	Challenge	Options/Opportunities
Fires	*Most families confirmed that no service providers reached out to them to see how the family/child were going and that service ceased through the period	*Better communication by service providers (also picked up in service provider outcomes) Include things like website/social media/communication/resources
	*All families had different experiences. Some chose to stay to keep family in routine, some evacuated.	*Work up case studies for those that stayed and those that chose to leave. What worked well? Access to Person-centered Emergency planning for parents/carers *Engage community services in emergency response
	*At least one family who evacuated were advised their home burnt later to be told it hadn’t	*Better systems at place by emergency responders to keep families informed if they chose to evacuate
	*Some recovery activities were run but were not ‘inclusive’ events and required the parent to stay or have a support worker support the child. Some children missed opportunities to engage.	*Ensuring all recovery programs are inclusive and are equipped with disability support workers to ensure inclusive practices for children with additional needs. Recovery centres and emergency responders to do training – is there a position to support?
	*Many families reported a change in children’s behaviours however pathways to specialist counselling were unavailable or not asked for.	*Trauma and counselling to take into consideration children with additional needs including those who may be non-verbal. Counselling to be offered as a family unit, not just individual Easier pathways – how can existing provider be resourced to do this?

All families had different experiences through the fires. Some families practiced evacuation with their children, others remained in the family home and some families were in and out of evacuation up to 10 times through the four-six week period depending on where they lived.

What is the data telling us?

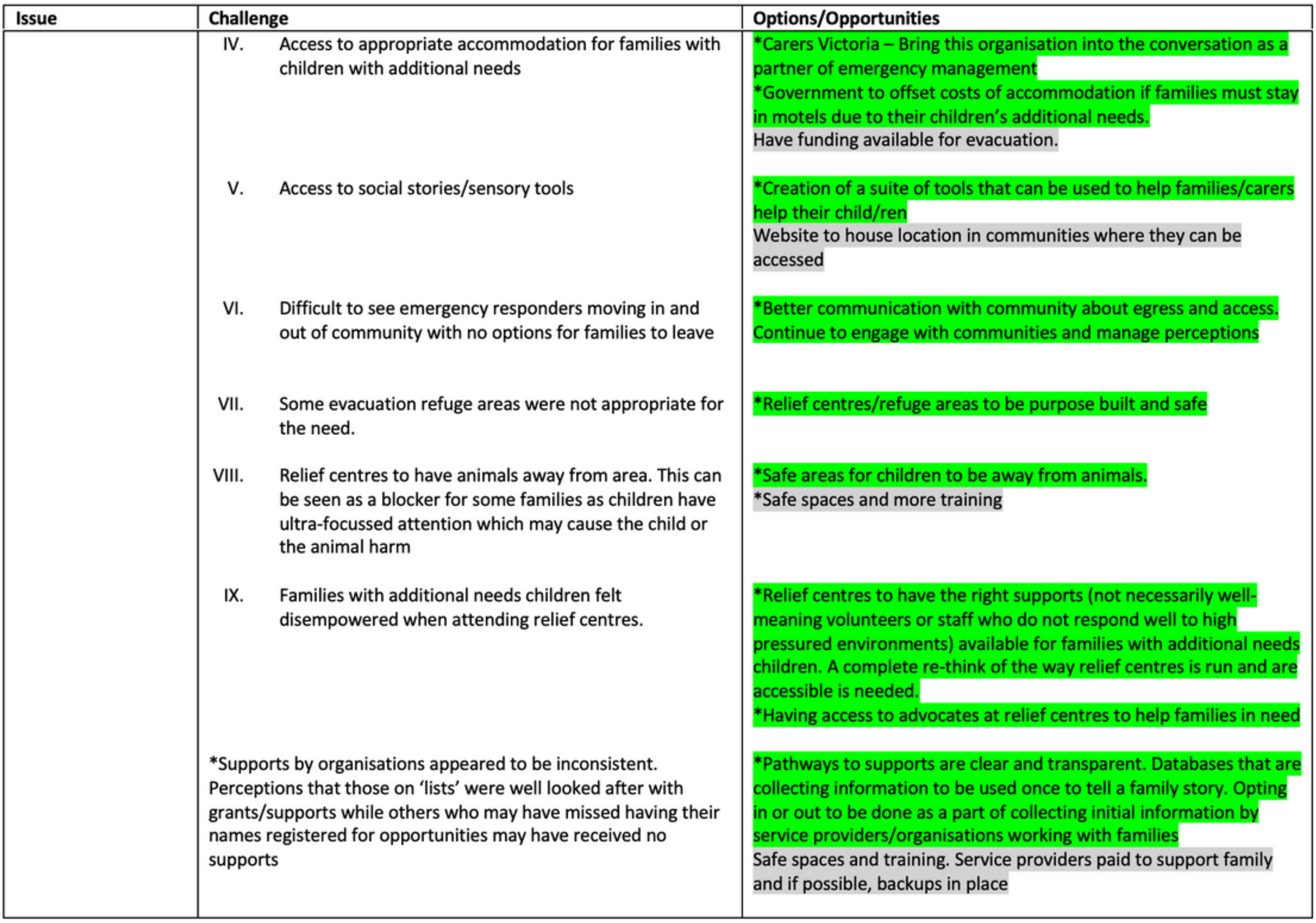


Issue	Challenge	Options/Opportunities
		Somewhere to move families to temp accommodation while receiving counselling
	*Case workers assigned to families through recovery did not have a disability background and therefore the right supports were either unavailable or it was easier for the families to do it by themselves.	*Case workers working with families/carers who have children with additional needs have experience in disability, including pathways to services and trauma counselling. When in attendance, have a Disability Support worker to help with the children while discussing issues with families/carers. Access to Disability Advocates at all times Gippsland Disability Advocate resourced before, during and after emergencies Improve intake to include information about needs Call local case managers to assist who have already been working with families
	Fire refuge areas and relief centres require better supports for families who have children with additional needs. I. Safety of children in large relief centres was a concern	*Designated safe zones for children with additional needs if child/ren are required to stay as a result of the emergency Spaces and tools to assist – what is there for children – sensory items to be supplied? Ability to go to 'safe' relief centres If family have safety concerns with ex-partners etc
	II. Messaging of emergency personnel located at fire refuge areas and relief centres caused panic	*Calmer conversations with those who are at evacuation points with local responders rather than those from out of town. Training of staff including defence forces
	III. Better access to advocates/qualified people	*Financial resources and entry given to advocates or people with better knowledge to work in relief centres Funding for Gippsland Disability Advocacy group

Lack of focussed trauma counselling for children with additional needs. Many families reported a change in behaviours after the fires however pathways to specialist counselling were non-existent. One child was unable to obtain assistance due to her son being non-verbal despite numerous requests to authorities.

Some recovery activities were run to help children but were not inclusive or required the child to have a support worker. This then excluded children with additional needs from recovery activities as support workers were not available in the townships that recovery activities were offered. A small number of children with additional needs missed these opportunities to engage.

What is the data telling us?



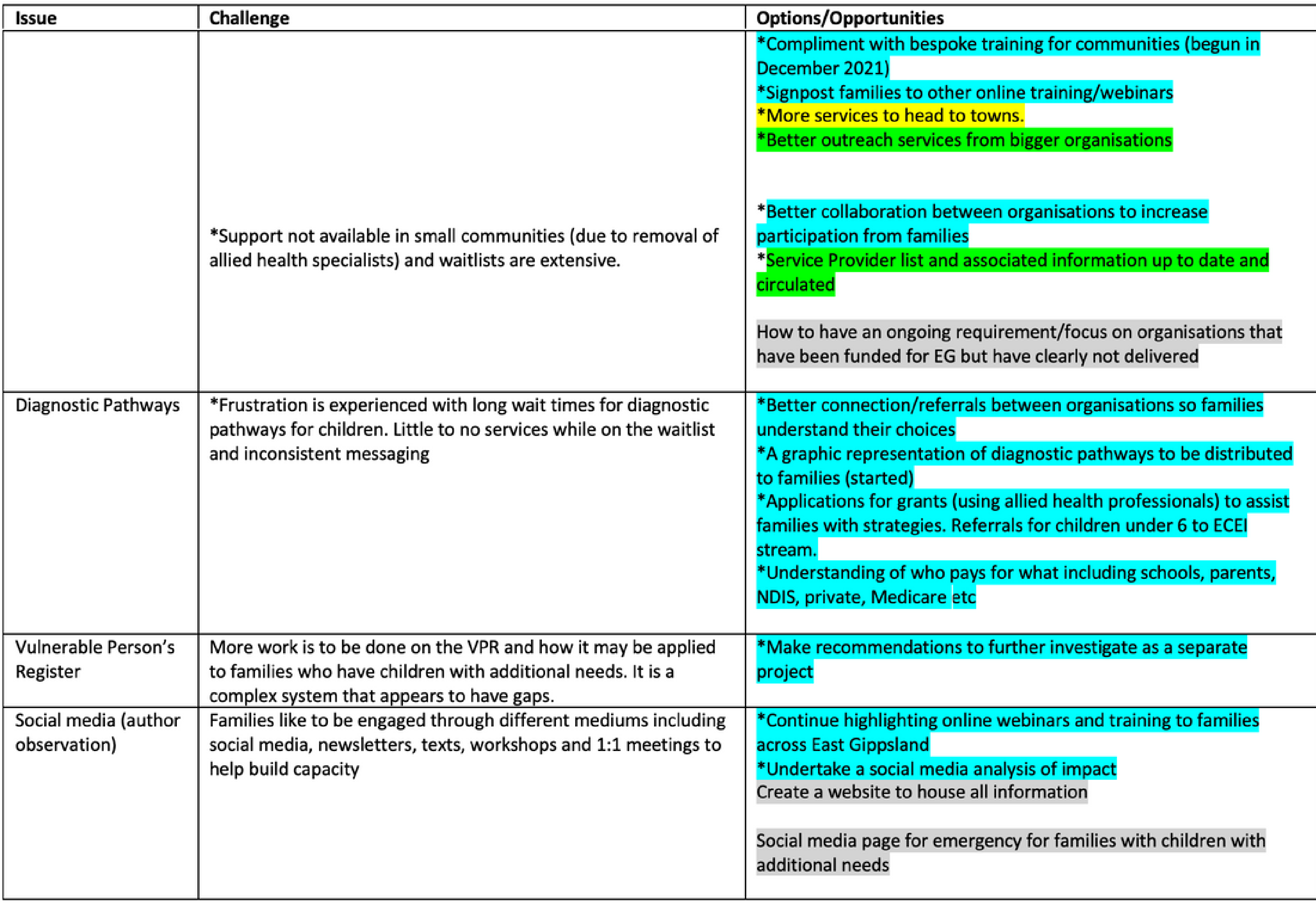
Issue	Challenge	Options/Opportunities
	IV. Access to appropriate accommodation for families with children with additional needs	*Carers Victoria – Bring this organisation into the conversation as a partner of emergency management *Government to offset costs of accommodation if families must stay in motels due to their children's additional needs. Have funding available for evacuation.
	V. Access to social stories/sensory tools	*Creation of a suite of tools that can be used to help families/carers help their child/ren Website to house location in communities where they can be accessed
	VI. Difficult to see emergency responders moving in and out of community with no options for families to leave	*Better communication with community about egress and access. Continue to engage with communities and manage perceptions
	VII. Some evacuation refuge areas were not appropriate for the need.	*Relief centres/refuge areas to be purpose built and safe
	VIII. Relief centres to have animals away from area. This can be seen as a blocker for some families as children have ultra-focussed attention which may cause the child or the animal harm	*Safe areas for children to be away from animals. *Safe spaces and more training
	IX. Families with additional needs children felt disempowered when attending relief centres.	*Relief centres to have the right supports (not necessarily well-meaning volunteers or staff who do not respond well to high pressured environments) available for families with additional needs children. A complete re-think of the way relief centres is run and are accessible is needed. *Having access to advocates at relief centres to help families in need
	*Supports by organisations appeared to be inconsistent. Perceptions that those on 'lists' were well looked after with grants/supports while others who may have missed having their names registered for opportunities may have received no supports	*Pathways to supports are clear and transparent. Databases that are collecting information to be used once to tell a family story. Opting in or out to be done as a part of collecting initial information by service providers/organisations working with families Safe spaces and training. Service providers paid to support family and if possible, backups in place

One family stated that they felt safe as they had prepared. They were reluctant to evacuate due to their child's disability and the child's need for routine.

One family evacuated to Melbourne and was advised their home had burnt down which they later found out it didnt.

One family presented to a fire refuge area. More support needs to be given to emergency responders from out of town to help them handle a refuge area and the families/individuals within it. Deep trauma has occurred from this families experience.

What is the data telling us?



Issue	Challenge	Options/Opportunities
	*Support not available in small communities (due to removal of allied health specialists) and waitlists are extensive.	*Compliment with bespoke training for communities (begun in December 2021) *Signpost families to other online training/webinars *More services to head to towns. *Better outreach services from bigger organisations *Better collaboration between organisations to increase participation from families *Service Provider list and associated information up to date and circulated How to have an ongoing requirement/focus on organisations that have been funded for EG but have clearly not delivered
Diagnostic Pathways	*Frustration is experienced with long wait times for diagnostic pathways for children. Little to no services while on the waitlist and inconsistent messaging	*Better connection/referrals between organisations so families understand their choices *A graphic representation of diagnostic pathways to be distributed to families (started) *Applications for grants (using allied health professionals) to assist families with strategies. Referrals for children under 6 to ECEI stream. *Understanding of who pays for what including schools, parents, NDIS, private, Medicare etc
Vulnerable Person's Register	More work is to be done on the VPR and how it may be applied to families who have children with additional needs. It is a complex system that appears to have gaps.	*Make recommendations to further investigate as a separate project
Social media (author observation)	Families like to be engaged through different mediums including social media, newsletters, texts, workshops and 1:1 meetings to help build capacity	*Continue highlighting online webinars and training to families across East Gippsland *Undertake a social media analysis of impact Create a website to house all information Social media page for emergency for families with children with additional needs

At least 80% of families asked to have access to social stories for both natural disasters, including fires for their communities. Social stories would also be welcomed at every refuge area or relief centre to help alleviate the anxiety in their children

At least three families have commented on the supports provided by organisations and departments. The perception is some got the world, and some have missed the opportunity to 'register on specific 'lists' so access to supports and grants have not eventuated

Some families had access to case managers. Families would like to see more case workers with a disability background. "I was being asked to fill in paperwork while my child was dis-regulated. It all got too hard and I never did it in the end."

At least four families have indicated they would only like one point of contact. They felt that they have missed out on opportunities because at times things moved very fast and were hazy, people who called and what they had promised were forgotten in the midst of immediate recovery.

What is the data telling us?

Issue	Challenge	Options/Opportunities
	*Families were asked too soon about their needs. Money spent on things that organisations thought were the right things, but families said they were not relevant.	*Have a process where communities set priorities rather than organisations vying for funding for recovery, particularly on longer term recovery. Stagger funding opportunities as immediate/medium/long term
Community	*There is a stigma attached to having children with additional needs which leaves families and children isolated	*Have more inclusive activities for their children to be engaged Training in Uni's and TAFES
Early Childhood Education/School	*School is hard to navigate, particularly regarding transitions (kinder to school, between grades, school to year 7, educational supports, reasonable adjustments, funding, diagnostic pathways)	*More conversations between teachers as the child/ren transition *More understanding of how to navigate the government school system *More conversations between early childhood and schools *Better support for teachers to help integrate children with additional needs into mainstream schooling, particularly in Far East Gippsland *Investigate an 'annexation' of the Bairnsdale Specialist School in Far East Gippsland *Create a document to help empower parents to have different conversations with schools (completed) *Schools accept child diagnosis and supports required. Work with DET on a project to develop working involving parents
NDIS	*Good support from a Commonwealth bus that was available through recovery efforts	*Continue efforts for bus to be available, particularly after recovery.
	*Local Area Coordinators (LAC) did not truly understand the impact of the fires on families and their children	*Better understanding and education of affects of the fire and limited options moving into covid for underspending plans.
	*LACs were disrespectful to parents and encouraged them to 'move closer to supports'	*Better understanding of feedback channels for NDIS participants and empowering families to lodge complaints
	*Misunderstanding of NDIS plans and how to use them (including choice and control)	*Training by NDIS Community Engagement team to work with communities to help them understand (feedback provided)

And some other insights...

Planned burning triggered at least half of the families' children during 20/21. More social stories to help children understand the difference between fires (emergency response) and planned burning would be extremely useful in communities subject to planned burning

Messaging around fires needs to be clear and simple. For those who have a cognitive condition or neurodiverse brain, the inconsistency between the Emergency App and localised information was confusing and put at least one family in severe danger.

Relief centres need to be more equipped for families/carers who have children with additional needs. Sensory packs, more access to advocates, billeting families and more understanding of disability within centres is required.

What is the data telling us?

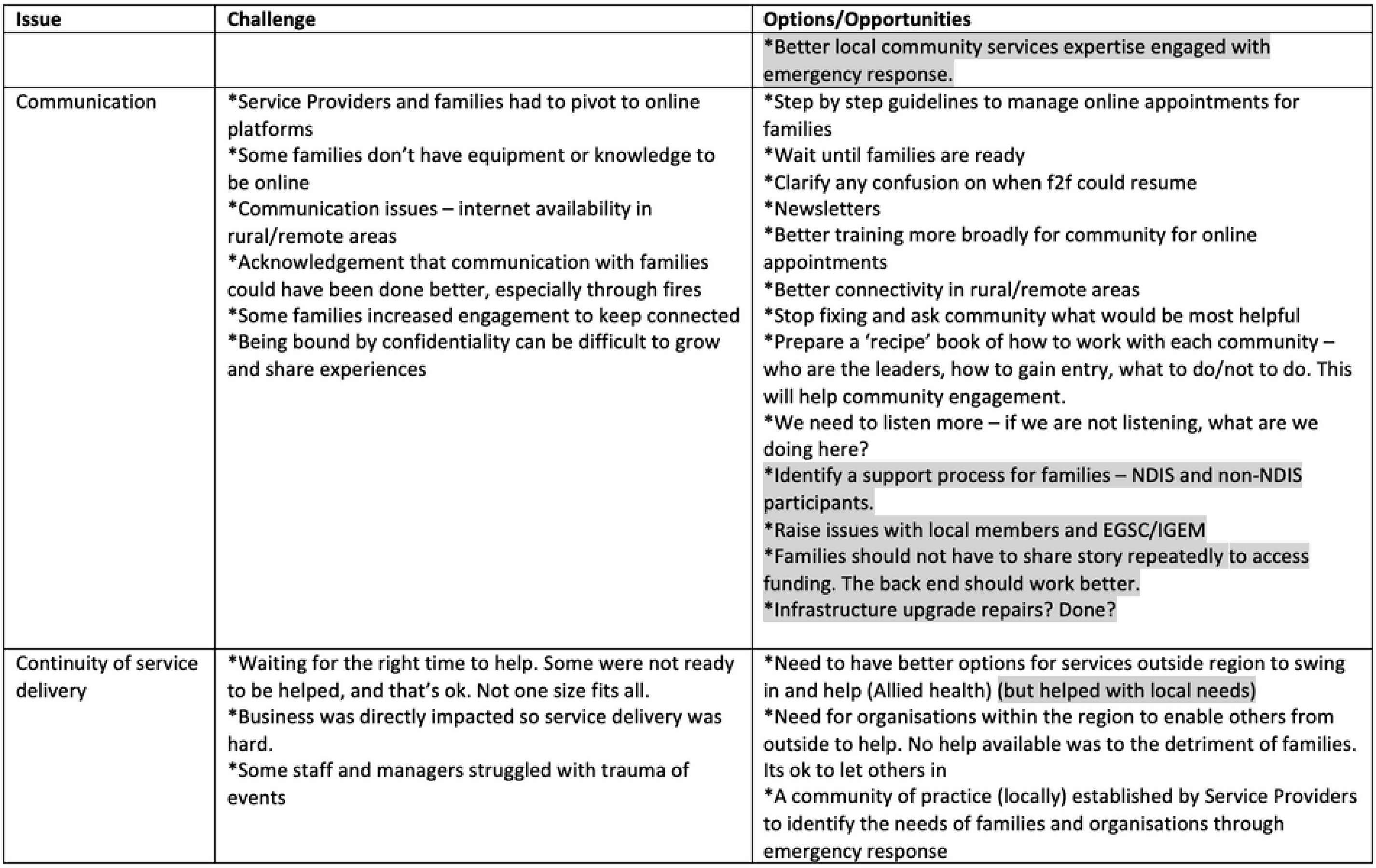
Table 5 - Insights and observations from Service Providers and Organisations

Fourteen Service Providers throughout East Gippsland have participated in the collection of information. Two Service Providers have declined the offer to participate. This information has been collected at a point in time (December 2021). This table was distributed to the CWANWG on 16 December 2021 as a part of a workshop to identify further options/opportunities, who might be responsible and what the priority might be. All new additions from the CWANWG group have been highlighted in grey. Areas in blue are common areas between families/carers information and service providers. Eleven questions were asked of each individual. Answers have been themed below.

Issue	Challenge	Options/Opportunities
Fires/Covid	*Families disengaged *Business models disrupted *Service delivery disrupted *Some services grew *Families found it difficult to engage in an online platform *Staff loss because of the fires *Need staff on the ground immediately after fires to manage influx of referrals.	*Activity packs delivered directly to participants and their families *Online telehealth *f2f where could *Phone calls *Use of existing contacts in the community to connect – but need community leaders to help *Worked with families on their needs over last 18 months *Work at some relief centres were invited *Newsletters *Continue to promote the Person-centered Emergency Planning (PCEP) process to help families prepare for emergency responses *Relief centres are poorly equipped – we need to do more to help them cater for the minority *Have allied health staff act as "consultants" to assist emergency response. This shouldn't be on a volunteer basis. *Produce 'evacuation packs' to help manage prepare families *Share resources across community – everyone should have the same information and use it. *Build capacity of emergency services to improve their language to be more inclusive.
		*Billeted accommodation is needed to help families/carers with additional needs children (there were people wanting to offer but there was no way to do so) *Everyone needs to understand the rights of the child and their diversity of needs *Creation of social stories, sensory resources in evacuation/relief/emergency centres (Birdie and the fire stories) *Stronger communication to help families know who to call if they need help. Often this is set up after a disaster and it's too late. Need better advanced planning and it made public to members of the community *Mobilise government services to better support children with additional needs. Ensure the channelling of funding is commensurate with the need by organisations and not for profits. (Local community service organisations) *More funding to implement the PCEP model *Community websites/letters *Work with EGSC *More training *Talk to EGSC Recovery/Response Emergency Management Committee and BRV/IGEM about what can be put in place *EGSC membership for crisis response champions from sectors that support all aspects of family support *Vulnerable Persons Register relevance and importance (and up to date) *Evacuation Centres – include expertise from community service orgs (local ones) *Find a place to stay – how could local families/nearby be engaged to offer suitable accommodation Case management Response – use specialist knowledge that exists. Harness all local expertise available. Not bring in staff without local knowledge across local organisations

What is the data telling us?

At least three providers identified that "We really needed to be patient...some people were just not ready to be helped, they were in survival mode"



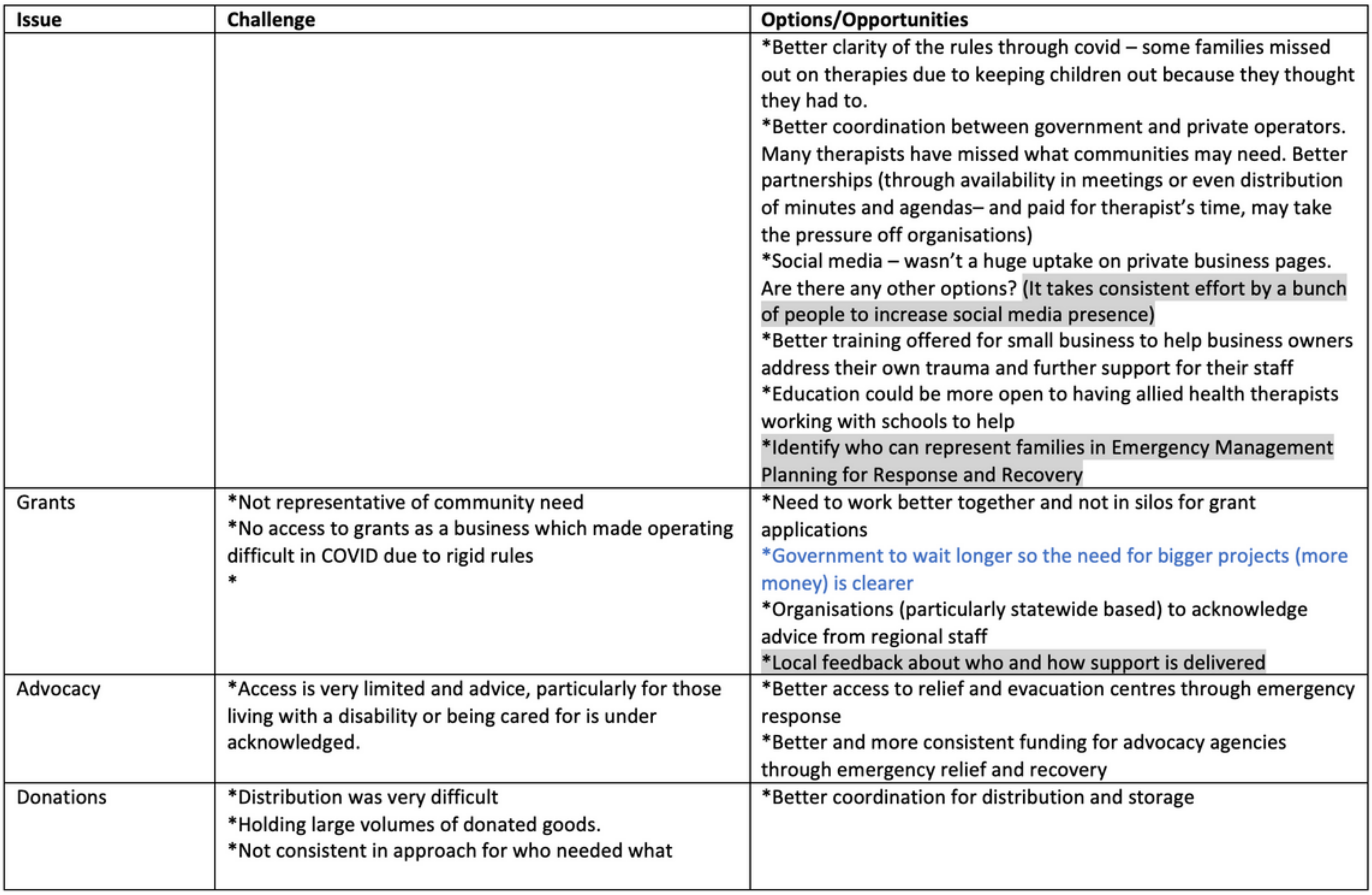
Issue	Challenge	Options/Opportunities
		*Better local community services expertise engaged with emergency response.
Communication	*Service Providers and families had to pivot to online platforms *Some families don't have equipment or knowledge to be online *Communication issues – internet availability in rural/remote areas *Acknowledgement that communication with families could have been done better, especially through fires *Some families increased engagement to keep connected *Being bound by confidentiality can be difficult to grow and share experiences	*Step by step guidelines to manage online appointments for families *Wait until families are ready *Clarify any confusion on when f2f could resume *Newsletters *Better training more broadly for community for online appointments *Better connectivity in rural/remote areas *Stop fixing and ask community what would be most helpful *Prepare a 'recipe' book of how to work with each community – who are the leaders, how to gain entry, what to do/not to do. This will help community engagement. *We need to listen more – if we are not listening, what are we doing here? *Identify a support process for families – NDIS and non-NDIS participants. *Raise issues with local members and EGSC/IGEM *Families should not have to share story repeatedly to access funding. The back end should work better. *Infrastructure upgrade repairs? Done?
Continuity of service delivery	*Waiting for the right time to help. Some were not ready to be helped, and that's ok. Not one size fits all. *Business was directly impacted so service delivery was hard. *Some staff and managers struggled with trauma of events	*Need to have better options for services outside region to swing in and help (Allied health) (but helped with local needs) *Need for organisations within the region to enable others from outside to help. No help available was to the detriment of families. Its ok to let others in *A community of practice (locally) established by Service Providers to identify the needs of families and organisations through emergency response

When asked "How did you reach out to families through fires and COVID? How did families respond" Eight of the fourteen interviewed said that Some/most families dropped off for a variety of reasons and businesses adapted to online and face to face where possible."

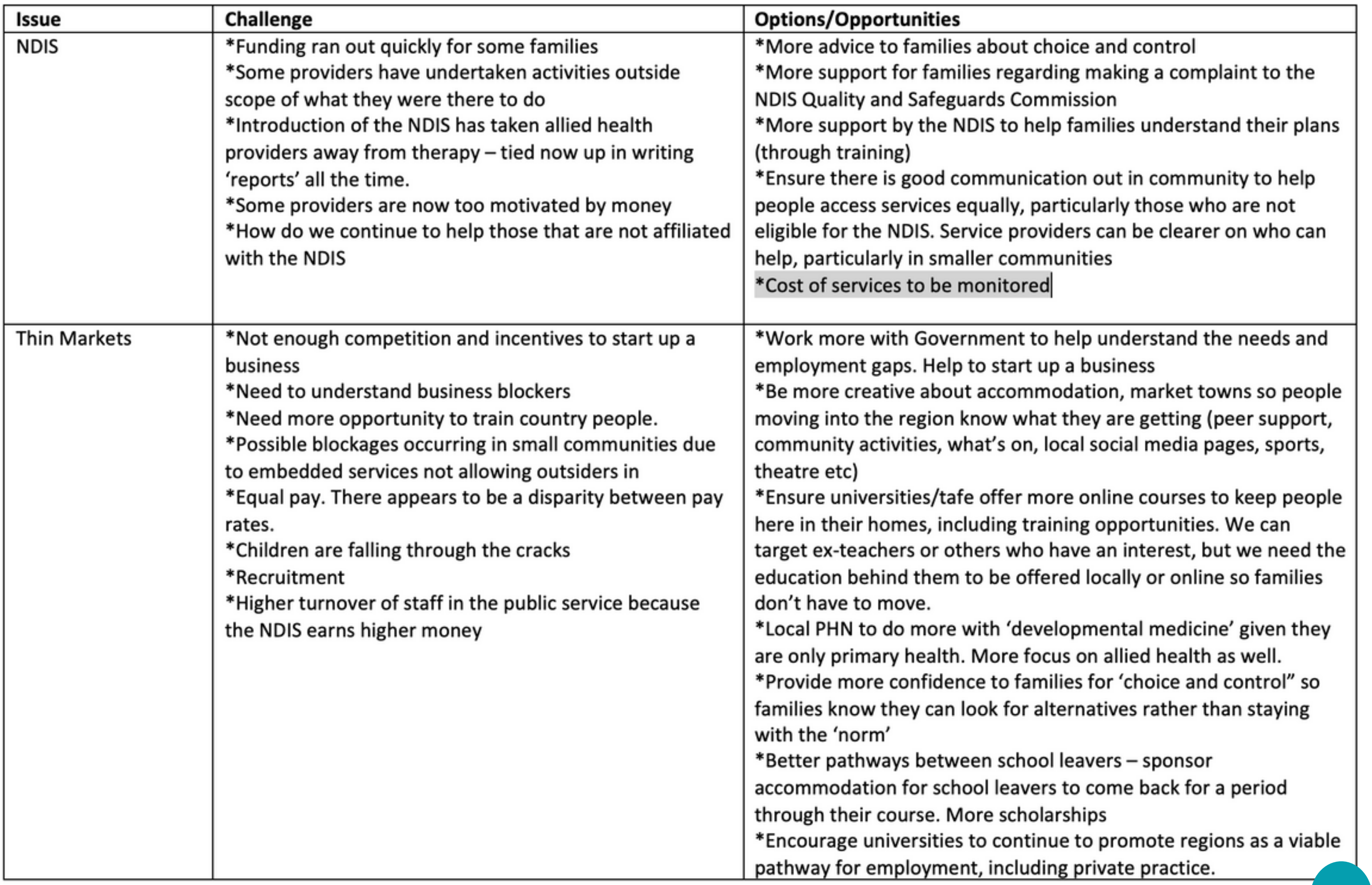
When asked **"Through COVID, how did you adjust your business to meet the needs of families and kids? Did you find many engage or did they drop off?"** At least 9 providers and organisations confirmed that many families disengaged and it got too hard, some re-engaged but many are still dealing with trauma (2) and many didn't have stable access to telehealth and IT to make online therapy work."

"We need to listen more - if we are not listening, what are we doing here?"

What is the data telling us?

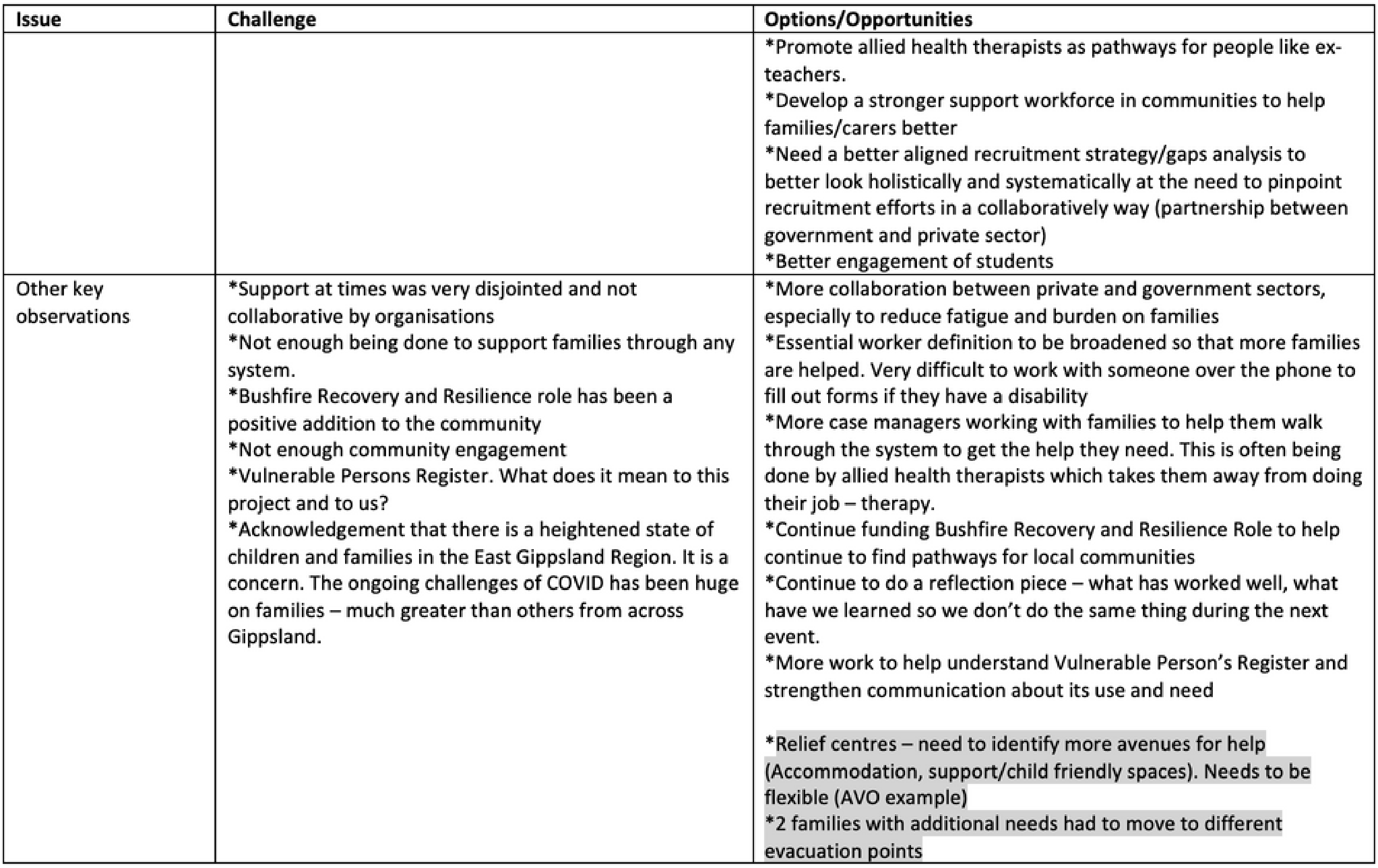


Issue	Challenge	Options/Opportunities
		*Better clarity of the rules through covid – some families missed out on therapies due to keeping children out because they thought they had to. *Better coordination between government and private operators. Many therapists have missed what communities may need. Better partnerships (through availability in meetings or even distribution of minutes and agendas– and paid for therapist's time, may take the pressure off organisations) *Social media – wasn't a huge uptake on private business pages. Are there any other options? (It takes consistent effort by a bunch of people to increase social media presence) *Better training offered for small business to help business owners address their own trauma and further support for their staff *Education could be more open to having allied health therapists working with schools to help *Identify who can represent families in Emergency Management Planning for Response and Recovery
Grants	*Not representative of community need *No access to grants as a business which made operating difficult in COVID due to rigid rules *	*Need to work better together and not in silos for grant applications *Government to wait longer so the need for bigger projects (more money) is clearer *Organisations (particularly statewide based) to acknowledge advice from regional staff *Local feedback about who and how support is delivered
Advocacy	*Access is very limited and advice, particularly for those living with a disability or being cared for is under acknowledged.	*Better access to relief and evacuation centres through emergency response *Better and more consistent funding for advocacy agencies through emergency relief and recovery
Donations	*Distribution was very difficult *Holding large volumes of donated goods. *Not consistent in approach for who needed what	*Better coordination for distribution and storage

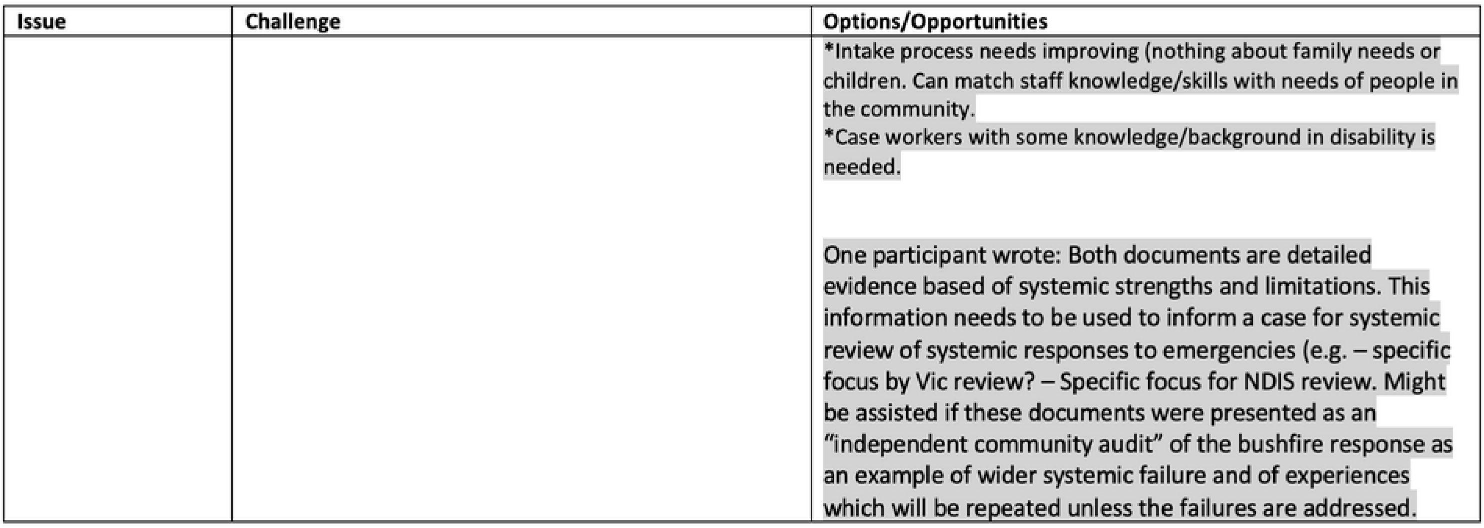


Issue	Challenge	Options/Opportunities
NDIS	*Funding ran out quickly for some families *Some providers have undertaken activities outside scope of what they were there to do *Introduction of the NDIS has taken allied health providers away from therapy – tied now up in writing 'reports' all the time. *Some providers are now too motivated by money *How do we continue to help those that are not affiliated with the NDIS	*More advice to families about choice and control *More support for families regarding making a complaint to the NDIS Quality and Safeguards Commission *More support by the NDIS to help families understand their plans (through training) *Ensure there is good communication out in community to help people access services equally, particularly those who are not eligible for the NDIS. Service providers can be clearer on who can help, particularly in smaller communities *Cost of services to be monitored
Thin Markets	*Not enough competition and incentives to start up a business *Need to understand business blockers *Need more opportunity to train country people. *Possible blockages occurring in small communities due to embedded services not allowing outsiders in *Equal pay. There appears to be a disparity between pay rates. *Children are falling through the cracks *Recruitment *Higher turnover of staff in the public service because the NDIS earns higher money	*Work more with Government to help understand the needs and employment gaps. Help to start up a business *Be more creative about accommodation, market towns so people moving into the region know what they are getting (peer support, community activities, what's on, local social media pages, sports, theatre etc) *Ensure universities/tafe offer more online courses to keep people here in their homes, including training opportunities. We can target ex-teachers or others who have an interest, but we need the education behind them to be offered locally or online so families don't have to move. *Local PHN to do more with 'developmental medicine' given they are only primary health. More focus on allied health as well. *Provide more confidence to families for 'choice and control" so families know they can look for alternatives rather than staying with the 'norm' *Better pathways between school leavers – sponsor accommodation for school leavers to come back for a period through their course. More scholarships *Encourage universities to continue to promote regions as a viable pathway for employment, including private practice.

What is the data telling us?



Issue	Challenge	Options/Opportunities
		*Promote allied health therapists as pathways for people like ex-teachers. *Develop a stronger support workforce in communities to help families/carers better *Need a better aligned recruitment strategy/gaps analysis to better look holistically and systematically at the need to pinpoint recruitment efforts in a collaboratively way (partnership between government and private sector) *Better engagement of students
Other key observations	*Support at times was very disjointed and not collaborative by organisations *Not enough being done to support families through any system. *Bushfire Recovery and Resilience role has been a positive addition to the community *Not enough community engagement *Vulnerable Persons Register. What does it mean to this project and to us? *Acknowledgement that there is a heightened state of children and families in the East Gippsland Region. It is a concern. The ongoing challenges of COVID has been huge on families – much greater than others from across Gippsland.	*More collaboration between private and government sectors, especially to reduce fatigue and burden on families *Essential worker definition to be broadened so that more families are helped. Very difficult to work with someone over the phone to fill out forms if they have a disability *More case managers working with families to help them walk through the system to get the help they need. This is often being done by allied health therapists which takes them away from doing their job – therapy. *Continue funding Bushfire Recovery and Resilience Role to help continue to find pathways for local communities *Continue to do a reflection piece – what has worked well, what have we learned so we don't do the same thing during the next event. *More work to help understand Vulnerable Person's Register and strengthen communication about its use and need *Relief centres – need to identify more avenues for help (Accommodation, support/child friendly spaces). Needs to be flexible (AVO example) *2 families with additional needs had to move to different evacuation points



Issue	Challenge	Options/Opportunities
		*Intake process needs improving (nothing about family needs or children. Can match staff knowledge/skills with needs of people in the community. *Case workers with some knowledge/background in disability is needed. One participant wrote: Both documents are detailed evidence based of systemic strengths and limitations. This information needs to be used to inform a case for systemic review of systemic responses to emergencies (e.g. – specific focus by Vic review? – Specific focus for NDIS review. Might be assisted if these documents were presented as an "independent community audit" of the bushfire response as an example of wider systemic failure and of experiences which will be repeated unless the failures are addressed.

"As one participant wrote: Both documents are detailed evidence based of systemic strengths and limitations. This information needs to be used to inform a case for a systemic review of systemic responses to emergencies...Might be assisted if these documents were presented as an "independent community audit" of the bushfire response as an example of wider systemic failure and of experiences which will be repeated unless the failures are addressed"

We need better access to relief and evacuation centres through emergency response.

What did we do and what did we learn?

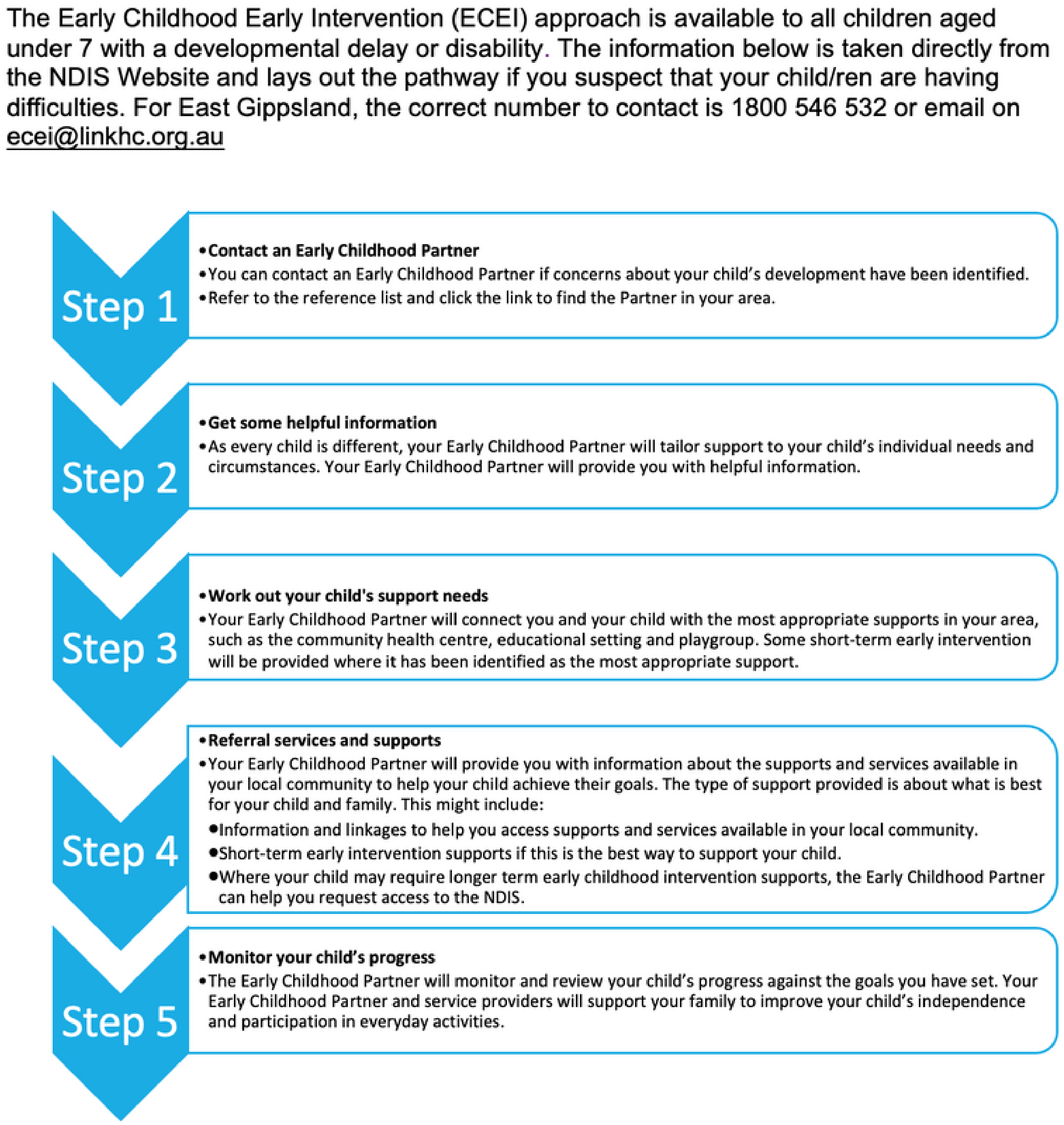
What did we do?

The National Disability Insurance Scheme - ECEI Pathway

An Early Childhood/Early Intervention (ECEI) step by step process was developed and adopted by the Children with Additional Needs Working Group in June 2021. It covers the steps for access and was developed in collaboration with the NDIS however final endorsement of the document rom the NDIS was never received.

There have been a number of attempts to develop a similar pathway for children/youth over 7. Information from the NDIS has changed consistently and requires almost monthly review. Given this, it was decided to ensure families have access to the NDIS website to follow access requirements. The NDIS ECEI Pathway Paper also has information for providing feedback and making a complaint if it is required. This document was sent to around 850 contacts across East Gippsland.

An excerpt from the NDIS ECEI Pathway Paper



The Early Childhood Early Intervention (ECEI) approach is available to all children aged under 7 with a developmental delay or disability. The information below is taken directly from the NDIS Website and lays out the pathway if you suspect that your child/ren are having difficulties. For East Gippsland, the correct number to contact is 1800 546 532 or email on ecei@linkhc.org.au

Step 1

- **Contact an Early Childhood Partner**
- You can contact an Early Childhood Partner if concerns about your child's development have been identified.
- Refer to the reference list and click the link to find the Partner in your area.

Step 2

- **Get some helpful information**
- As every child is different, your Early Childhood Partner will tailor support to your child's individual needs and circumstances. Your Early Childhood Partner will provide you with helpful information.

Step 3

- **Work out your child's support needs**
- Your Early Childhood Partner will connect you and your child with the most appropriate supports in your area, such as the community health centre, educational setting and playgroup. Some short-term early intervention will be provided where it has been identified as the most appropriate support.

Step 4

- **Referral services and supports**
- Your Early Childhood Partner will provide you with information about the supports and services available in your local community to help your child achieve their goals. The type of support provided is about what is best for your child and family. This might include:
  - Information and linkages to help you access supports and services available in your local community.
  - Short-term early intervention supports if this is the best way to support your child.
  - Where your child may require longer term early childhood intervention supports, the Early Childhood Partner can help you request access to the NDIS.

Step 5

- **Monitor your child's progress**
- The Early Childhood Partner will monitor and review your child's progress against the goals you have set. Your Early Childhood Partner and service providers will support your family to improve your child's independence and participation in everyday activities.

What did we learn?

Data collected has provided an extremely valuable insight into how families and carers managed through an unprecedented period with their children and more importantly, what community organisations and those working in the sector can use to embed best practice when planning for families and carers who have children with additional needs. This data has also enabled the Children with Additional Needs Working Group to identify areas of future need, particularly with regards to Emergency Management, the National Disability Insurance Scheme, Education and Diagnostic Pathways. All information received from families and carers were subject to a workshop in December 2021 and key priorities moving into 2022 and 2023 have now been mapped and form part of future grant processes.

It is clear from the insights of families and carers that practices are required to change. Next steps for the Children with Additional Needs Working Group are continue working with those individuals in positions of authority and key decision makers to ensure this feedback is embedded in any future planning.

Information regarding the NDIS is changeable almost daily which makes it very hard for families/carers and service providers to 'keep up' with the most relevant information.

Key NDIS decision makers have been provided with outcomes of this report and repeated attempts have been made to encourage more conversation within the East Gippsland community which has not yet occurred. Further attempts will be made by the CWANWG to re-engage, collaborate on feedback pathways and community engagement.

Reflections

- NDIS changes mean that mapping pathways for over 7 has been difficult to keep up with.
- The basis of the project was to seek information, explore gaps and opportunities. Key information has now been presented in various forums and priorities for the future have been developed
- Thin markets (gaps in service provision) is very difficult, especially in small remote communities.
- Systemic changes are required to ensure that families and carers are receiving the supports still needed, almost three years post Black Summer fires.

Supporting evidence for Objective 2:
CWANWG 16 December 2021 Prioritisation Workshop
ECEI Pathway Document (to be housed on Information Hub)
Minutes of CWANWG meetings (from May 2021 - July 2022)
Monthly dashboard of Project (from May 2021 - July 2022)
Emergency Management Reform Project Discussion Paper

Section 2.2: Work with key groups like Amaze and VALID to promote their availability across Gippsland by:

Investigating availability and their reach into regional areas like East Gippsland, including in times of emergency.

What did we do?

Work was undertaken early in the BRRP to understand where resources were available and whether there was an opportunity to travel to East Gippsland.

Amaze is a Statewide Autism Service providing online and over the phone support. They also provide training through workshops (face to face and online). East Gippsland were the recipients of a number of training opportunities including in Cann River, Orbost and Bairnsdale. COVID played a critical role in limiting face to face opportunities and a number of Early Days Workshops were held online. Anecdotally, those who were participant's enjoyed the workshops. Orbost enjoyed their time together so much that they have now formed their own 'carers' group which is facilitated by Gippsland Disability Advocacy. The group welcomes carers who themselves may have a disability to get together monthly and network. This currently has around 8 parents/carers and is an excellent result which started with the Amaze Workshops.

Other opportunities to engage with support services has come through Association of Children with Disability (ACD) (Statewide Service), Gippsland Disability Advocacy (Advocates located in Bairnsdale and the Latrobe Valley), VALID (Statewide service with supports located in East Gippsland) and Amaze (Statewide service with training facilitators located in East Gippsland).

Through the feedback sessions, the need for advocates to be based in Relief Centres/Evacuation Points was made strongly. Advocate Groups like GDAI have indicated that they were severely underfunded to reach the true need of the families and carers who required their service.

VALID and GDAI also offer carers days and support groups to families and provide supports directly with people with a disability but most activity is centered in Bairnsdale or Sale. While most employees are based in either Bairnsdale or further west in the Latrobe Valley, the needs of families/carers and individual's themselves appear to be limited further east of Bairnsdale however advocates do have a stronger presence throughout the east than other groups.

The coverage within East Gippsland is determined on business need and as more families/carers become aware of these services, in time, more presence may be advocated for into the future. Many families do not know that services like these exist.

What did we learn?

Reflections

- Further work to secure funding to have a stronger advocate voice is required in times of emergency, especially at relief and evacuation centres. This includes future planning and prioritising in preparedness for attendance (and being allowed to enter relief and emergency centres) to assist families/carers and participants.
- Employee distribution is commensurate with need and funded accordingly to ensure East Gippsland is provided with the same fairness and equity to services as others.
- Families need to know these services are available, particularly in East Gippsland. This can be done through sharing of services through social media platforms that are meaningful to parents/carers (like community pages). To do this though, organisations themselves need to change their policies to enable sharing through social platforms rather than rely on their own organisational pages which we know parents/carers are not part of.
- Continue sharing online workshops and face to face opportunities for families.

What did we do?

Section 2.3: Develop and maintain a service provider list and update quarterly for families through:

Continuation of monitoring and updating of the service provider list and work with the EGSC and GLCH for extending reach and version control

The CWANWG was developed to overcome a critical need of understanding what services and supports were needed for families across East Gippsland. While much of the services/supports are East Gippsland based, further work to share how supports can be managed differently by the participants themselves, their families and carers and most importantly to have 'choice and control'.

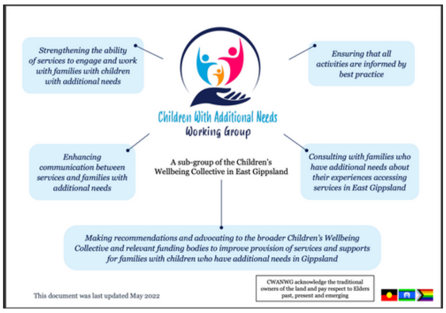
The Service Provider list is an "at a point in time" to allow services to be changed and managed as new services join East Gippsland.

The original version of the Service Provider list was shared across 850 contacts across East Gippsland including schools, bush nurses and early childhood services, and with families/carers themselves either through email or listed on social media pages.

While some families and carers welcomed the Service Provider list, others were concerned that they may not have had the most up to date version. All efforts are being made by the CWANWG to update quarterly, with Gippsland Lakes Community Health playing a lead role in its content updating through feedback received from CWANWG members or others in the community.

The Service Provider list can also be found on the Gippsland Disability Advocacy website and the East Gippsland Shire Council also has an easy language version for families/carers and participants to consider. A media release was created for the distribution of the document in June 2021 to help connect participants/families and carers.

The intention is to house the Service Provider list on the CWANWG Information online Hub once it has been established. It will provide participants/families and carers with the confidence to know that when it is updated quarterly by the Gippsland Lakes Complete Health team, it will be the most recent version.



Strengthening the ability of services to engage and work with families with children with additional needs

Ensuring that all activities are informed by best practice

Children With Additional Needs
Working Group

Enhancing communication between services and families with additional needs

A sub-group of the Children's Wellbeing Collective in East Gippsland

Consulting with families who have additional needs about their experiences accessing services in East Gippsland

Making recommendations and advocating to the broader Children's Wellbeing Collective and relevant funding bodies to improve provision of services and supports for families with children who have additional needs in Gippsland

This document was last updated May 2022

CWANWG acknowledge the traditional owners of the land and pay respect to Elders past, present and emerging

About the Service Provider List

This "One Stop Shop" Service Provider list has been brought together to help families find the services they need in East Gippsland. Families have told us overwhelmingly that they would like information in one place to help them find the right services for their child/children. This is the Children with Additional Needs (CWAN) working group response to help families connect with service providers.

Due to the nature of change, this list is one that will be updated every three months by a member of the CWAN working group. The "One Stop Shop" Service Provider list has been developed at **a point in time** and is not an exhaustive list. We have provided a checklist to help you ask the questions of the service providers you intend to use, particularly around the location they work from, costs for their service and their availability.

If you are aware of other services you would like to add (including those that service East Gippsland from other areas including Melbourne), please email Kara Goodwin at Gippsland Lakes Complete Health: karag@glch.org.au so it can be added to the next update.

Children With Additional Needs
Working Group

Sustainability success: Gippsland Lakes Complete Health have confirmed that they will continue to update this document into the future. If you know of any additions or changes - please contact Kara at karag@glch.org.au

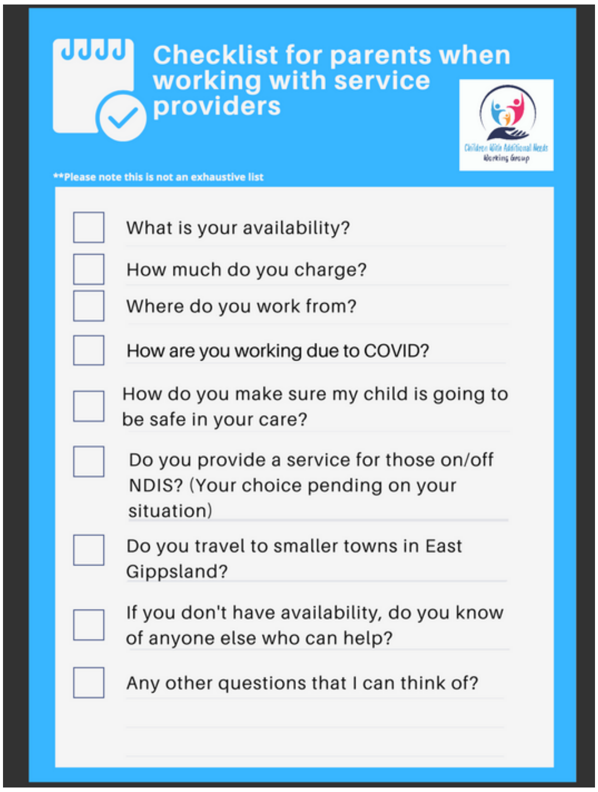
To bring the Service Provider List together, all service providers and supports were contacted directly to ensure that they were still current, operational and happy to be 'on the list'. They were also provided with the opportunity to update their details, and confirm contact and what they do to help families. Also created was a 'checklist' of questions to assist families and carers to ask the right kind of questions to promote a better understanding of services, especially if their child/ren have been recently diagnosed.

Support for Carers

What support do I need?	Who can help?	Who can I contact if I need more information?	What does this provider do?
Support as a carer	Carers Gateway	1800 422 737 www.carergateway.gov.au	Provides practical advice and support, counselling, peer support and respite
Transport support for specialist medical treatment	Victorian Transport Assistance Scheme	https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply	Victorian Patient Transport Assistance Scheme (VPTAS) covers some of the travel and accommodation costs incurred by rural Victorians when they must travel more than 100 kms one way for specialist medical treatment

Inclusion Support in Childcare, Kinder and School

What support do I need?	Who can help?	Who can I contact if I need more information?	What does this provider do?
Support for my child at childcare	Yooralla – access through childcare	Contact your childcare centre, after school and holiday care service to discuss supports	Childcare centers and programs can access support to improve the inclusion of children with additional needs in their care.
Support for my child at Kinder	Uniting - access through Kindergarten	Contact your child's Kindergarten to discuss supports	All Kindergartens can apply through the Kinder Inclusion Support (KIS) program to access support for children with additional needs to improve inclusion in the kinder setting.
Support for my child at school- student support groups	Association for Children with a Disability	More information at - https://www.acd.org.au/student-support-groups/ or 1800 654 013	The Student Support Group (SSG) brings together everyone involved in your child's education to plan supports and follow their progress.



Checklist for parents when working with service providers

**Please note this is not an exhaustive list

☐ What is your availability?

☐ How much do you charge?

☐ Where do you work from?

☐ How are you working due to COVID?

☐ How do you make sure my child is going to be safe in your care?

☐ Do you provide a service for those on/off NDIS? (Your choice pending on your situation)

☐ Do you travel to smaller towns in East Gippsland?

☐ If you don't have availability, do you know of anyone else who can help?

☐ Any other questions that I can think of?

What did we learn?

Reflections

- The Service Provider list has been an invaluable asset for many families across East Gippsland. Many families/carers did not know the breadth of services and supports available (current supports did not share this information or refer families, instead keeping them on their own 'wait list' to the detriment of the child/ren being supported).
- Organisations and providers to share this document, particularly if they have wait lists to enable participants, families and carers to have 'choice and control' and to promote a more collegiate approach to the needs of children with additional needs.
- The Service Provider list needs to be available in one spot so that those who use it can have confidence that they have the latest version. It is the expectation of the CWANWG that it will be available on the online "Information Hub" by July 2022.

Supporting evidence for Objective 2.3:
*Media Release for Service Provider List

*Service Provider list and checklist (to be housed on Information Hub)

"The Service Provider list is a fantastic idea. My only issue is version control. I need to feel confident that what I am using is the latest version."

Case Study - An organisational perspective

A Joint Fuel Management Plan is a series of planned burns within a management plan that agencies use to plan a region's fuel management program. One particular planned burn was nominated to be undertaken as part of an Autumn burn program in 2021, within East Gippsland.

As a part of the engagement process, the agency encourages community members that live near particular planned burns, to talk with agencies about timing and scheduling of activities. Planned burn notification letters are also sent to householders/landowners, and flyers placed in public areas to inform community of when they are going to be occurring.

As a result of a flier being posted, one family contacted the agency to gain further information regarding the planned burn and requested to talk to a supervisorThe conversation highlighted the families concerns as one of their children has a fascination for and with fire (on several occasions has lit a fire in the home). The supervisor assured the family that they would be informed of the planned burning date, so the family could remove the child from the property to participate in other activities for the day.

The family received a phone call from the agency with a nominated planned burn date and they made alternative arrangements to cover the following two days when the burn was planned to proceed.

After the burn was undertaken, the crews continued to patrol the area for a further 2 days to ensure the burn was safe. During this patrolling phase, the crews were briefed by the burn controller to conduct activities in the vicinity of the family home with care and consideration. Any conversations about the fire and the activity or any physical works being undertaken were to be done with the utmost care.

During one of the patrols, the child was in the family's back yard playing with his mother and sibling, when 2 fire crews in fire vehicles stopped to attend to a burning stump. The child ran towards the back fence waving and calling out. One of the crew members were able to 'distract' the child by allowing the child inside the patrol vehicles, tooting the horn and talking about the family dog while other crew members continued with their task unnoticed.

Lessons learned

- Good communications, understanding the circumstances and respectful relationships have been made between the family and the agency for considerations with future programs in the area.
- Another highlight was that the family felt safe enough to approach the agency and share the opportunity with the agency.

Objective 3: Improve feedback from children and families to improve support services

What did we commit to?

HOW	TASKS	STATUS
3.1: Work with key providers to understand how they capture feedback from children and families about the service they provide	Interviews and 1:1 appointments for local service providers regarding how they undertake feedback and business improvement processes	✓
3.2 Build capacity of local services to have feedback process for hearing the experiences of children and families	Invite stories from families to share with providers and decision makers regarding emergency response and explore challenges and opportunities	✓
3.3 Hearing about the supports and interventions that make a difference in recovery and building resilience skills to manage future disasters	Sharing of stories to service providers from families to BRV, EGSC through personal meetings, presentations or through scenarios/case studies	✓

What did we do and what did we learn?

What did we do?

Section 3.1: Work with key service providers to understand how they capture feedback from children and families about the service they provide through:
Interviews and 1:1 appointments for local service providers regarding how they undertake feedback and business improvement processes.

A survey was undertaken with fourteen service providers and organisations working directly with families/carers who have children with additional needs. Three questions out of the survey were in direct relation to understanding business improvement processes and how they undertake feedback.

Question 1: How do you know if you are doing a good job? What does it look like (multiple answers were offered)

6 providers said they hear good feedback directly from families
5 providers have a survey/questionnaire
4 providers said they have active attendance/engagement with their service
3 providers currently have a wait list (inference is they are busy so they must be doing a good job)
2 providers said their clients respond well to therapies
2 providers said they have referrals from other clients or service providers to service
2 providers said they don't do it well
2 providers said they need to turn it around and ask families - how would feedback look for you?

Question 2: Would you like to see feedback more formalised? Do you run your own surveys for satisfaction?
7 providers said they run their own feedback
4 providers said their feedback was done verbally
2 providers said no, they do not want to formalise feedback

Question 3: We are looking at trialling a more holistic evaluation across a number of providers, is this something you would be interested in joining to ensure families can provide feedback in a consistent way?
4 providers said they would like to co-design evaluation with families and ensure its person-centered
4 providers said maybe but do not want a 'middle person' telling them how to run my business. Prefer to use a safe space for feedback rather than anonymous feedback
2 providers said they would need to look at the interventions/outcomes of why we are asking for feedback before engaging
2 providers said no, they do not want to engage

What did we learn?

Reflections

- Some service providers are interested to co-design an evaluation/survey to capture family/carer needs and responses. Providing an opportunity to co-design evaluation/survey between willing providers and families should be a priority to help with consistency of service and feedback.
- Families may experience being on waiting lists because they are unaware of other providers being available.
- Anecdotally, some families have also experienced a power imbalance and are too worried about sharing their feedback for fear of being removed from provider 'books' in communities that are under-serviced, particularly since the fires. Families/carers are more unlikely to say anything to ensure they can keep their children in therapy as waitlists for other services can be over 12 months.

What did we do and what did we learn?

What did we do?

Section 3.2: Build capacity of local service providers to have feedback process for hearing the experiences of children and families by:
Inviting families to share their stories with providers and decision makers re: emergency response and explore challenges and opportunities.

Many hours were spent with families talking about their experiences through fire, recovery and COVID. These discussions took place face to face, follow up phone calls, conversations through email, workshops and the collections of stories from ten families who were brave enough to share.

The collation of stories from families and two organisations have been brought together in a document called "Family and Organisational Stories". Some stories have also been shared through this document as case studies. This report will also form the basis of the next iteration of work to begin in August 2022 which will look at inviting a group of emergency managers and organisations to form a working group and hear from families about their experiences through case studies and presentations of evidence based information.

Over 350 meetings have also occurred where information collected has been shared. In one instance, one emergency management organisation is now looking at how to further embed social stories about their work with their local communities. Community Recovery Committees in Buchan, Mallacoota, Clifton Creek have also been briefed on some of the key outcomes of the work and have provided support for continuation. Meetings have also been held with Bushfire Recovery Victoria Staff, key community organisations and the EGSC has been appraised of information.

Work by members of the CWANWG will continue to highlight the needs of our East Gippsland community over the next 12-18 months and will continue to prioritise work highlighted in Table 4 and Table 5.

Two families have been supported to attend the Disability Royal Commission as a result of these conversations.

What did we learn?

- Information sharing was compromised due to the timing of new grant applications coming through. At a time where the development of a strong engagement plan was required, the CWANWG members were required to pull submissions together for grants to continue some of the key priorities of work. This meant that the sharing of information which was intended, was unable to happen, particularly with Community Recovery Committees (CRC's), because everyone was focussed on grant applications.
- Starting the write up of the final report to begin earlier to enable a more considered approach to working with CRC's who themselves were very busy attending to their own grant processes.
- There is a real interest in the work given the cohort of the people sharing their story. Whether this is backed up by the systemic changes needed is yet to be seen or experienced.

What did we do and what did we learn?

What did we do?

Section 3.3: Hearing about the supports and interventions that make a difference in recovery and building resilience skills to manage future disasters through:
Sharing of stories to service providers, BRV and EGSC through personal meetings/presentations or through scenario/case studies.

The collection of stories from both families and organisations has provided decision-makers with a unique insight into how to better accommodate families/carers who are caring for children with additional needs.

Over 350 meetings have also occurred where collected information has been shared. In one instance, one emergency management organisation is now looking at how to further embed social stories about their work into their local communities. Meetings have also been held with Bushfire Recovery Staff, key community organisations and the EGSC has been appraised of information throughout the duration of the project (through minutes of CWANWG meetings) and connection with place-based managers.

Further work will continue to ensure the results of this report are embedded within community and organisations. Presentations to BRV, Gippsland Disability Advocacy and CWANWG members have been confirmed between July and September 2022. Meetings with Community Recovery Committees and placed based managers are also being negotiated.

Service providers and organisations were also asked about how they could contribute to building resilience within community. The following information was collected:

4 providers said they would use the Person Centered Emergency Planning Workbook as a vehicle to help families plan.
4 providers said that there needs to be more done in emergency planning
3 providers said that there was great work being done by the BRRP Project Lead

Many other outputs were developed and implemented through the life of the BRRP and were responsive to the needs identified by families and carers.

These included a number of documents developed and circulated to through a contact list of around 850 community members, staff from organisations and not for profits and local service providers. Some of these documents/reports included the following:

Completed:

SCHOOL - THE IMPORTANT STUFF

CWANWG Presents...

Your 'GO TO' School Resource Guide 2021

For help navigating the Government Schooling System for Children with Additional Needs in East Gippsland 2021

A "Go To" resource for all things school to assist with transitions and ensuring support (reasonable adjustments) are made for children with additional needs

NDIS 101 - Come and join us!

A free 2 hour workshop to help you understand and use your NDIS plan

1. What is the NDIS?

2. What is a NDIS Plan?

3. How to use your NDIS plan

4. How to use your choice and control

Session 1 - Wednesday 1 December from 7pm - 9pm

Session 2 - Thursday 2nd December from 10am-12pm

This is an inclusive event and everyone with a NDIS plan or a service provider is welcome!!

This event is brought to you by the Children with Additional Needs Working Group & Annette Axen - Paradigm to Empowerment

For registration - Jodie Simpson on 0407 372 036 or jodie@jodiesimpsonconsulting.com.au

A number of NDIS sessions run (Mallacoota, Buchan and Bairnsdale) to assist with family/carer understanding of the Scheme.

EMERGENCY MANAGEMENT REFORM PROJECT – DISCUSSION PAPER 2022

THE COLLABORATORS FOR THIS PROJECT WOULD LIKE TO ACKNOWLEDGE THE FIRST CUSTODIANS OF THE LAND WHICH WE LIVE AND WORK. WE PAY OUR DEEPEST RESPECTS TO ELDERS PAST, PRESENT AND EMERGING.

A Discussion Paper developed to inform the next phase of priorities regarding Emergency Management

There is a planned burn-off in my area

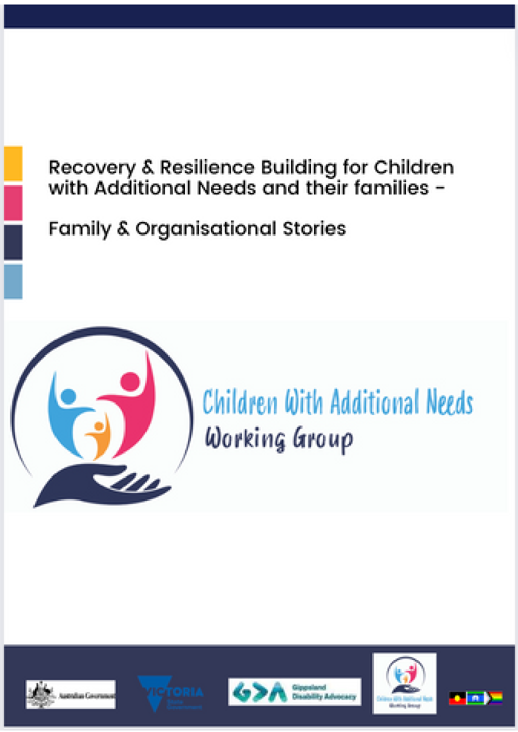
A social story to help children and adults with additional needs to have the information they need to feel calm and safe when planned burn-offs are happening in their area.

A Social Story developed in collaboration with the Department of Environment, Land, Water and Planning, Communikate Speech Therapy and CWANWG

Completed:

Going to my vaccination centre to get my COVID 19 Vaccine (Lucknow Hall, Bairnsdale).

A Social Story developed and circulated to help children with additional needs prepare for their COVID vaccinations as there was nothing available in our East Gippsland Community. Circulated and used widely by health professionals across East Gippsland as details could be changed to suit local community needs.



Recovery & Resilience Building for Children with Additional Needs and their families –

Family & Organisational Stories

Children With Additional Needs Working Group

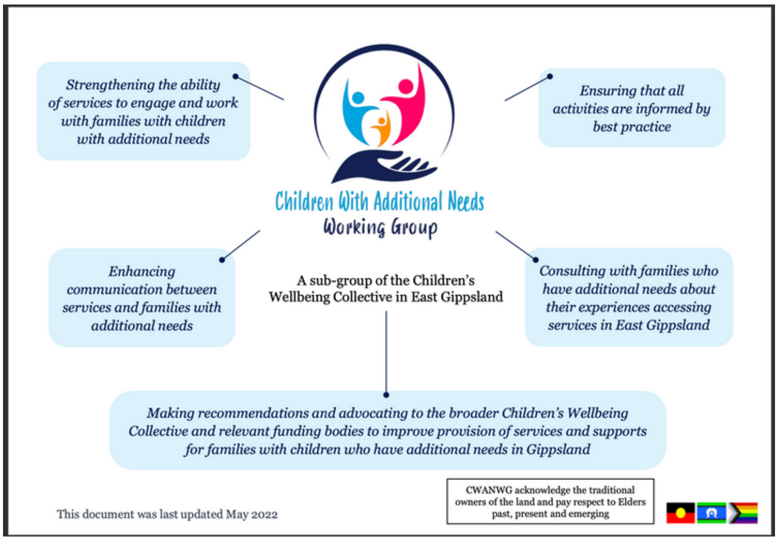
Family and Organisational stories all in one place

Sensitive Santa 2021 - Evaluation

Children With Additional Needs Working Group

Opportunity for children with additional needs to meet Sensitive Santa due to exclusion from many local events

Completed:



Strengthening the ability of services to engage and work with families with children with additional needs

Ensuring that all activities are informed by best practice

Children With Additional Needs
Working Group

Enhancing communication between services and families with additional needs

A sub-group of the Children's Wellbeing Collective in East Gippsland

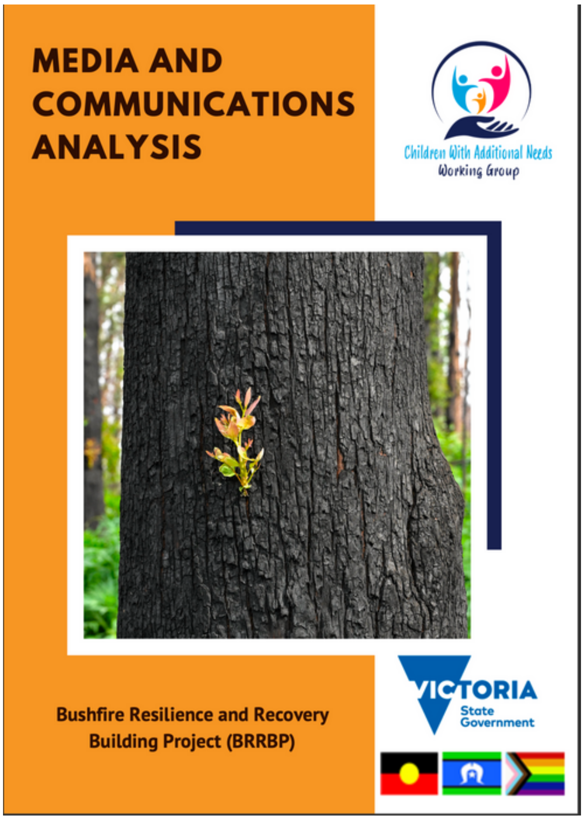
Consulting with families who have additional needs about their experiences accessing services in East Gippsland

Making recommendations and advocating to the broader Children's Wellbeing Collective and relevant funding bodies to improve provision of services and supports for families with children who have additional needs in Gippsland

This document was last updated May 2022

CWANWG acknowledge the traditional owners of the land and pay respect to Elders past, present and emerging

Service Provider List to help families connect to local providers



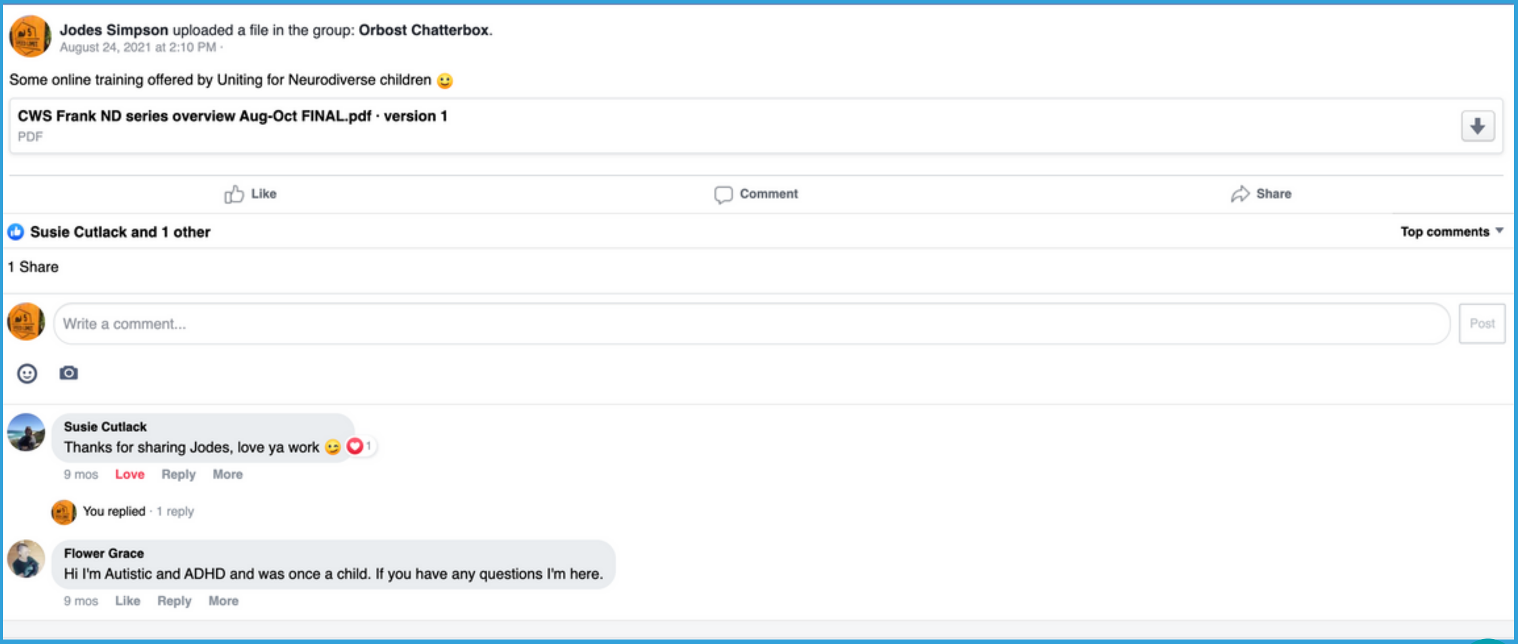
MEDIA AND COMMUNICATIONS ANALYSIS

Children With Additional Needs
Working Group

Bushfire Resilience and Recovery Building Project (BRRBP)

Analysis of media and communications used throughout the project including recommendations which identified a need to have an online "information hub" for families to access

Example of social media platform used to share information about upcoming workshops across East Gippsland



Jodes Simpson uploaded a file in the group: **Orbost Chatterbox**.
August 24, 2021 at 2:10 PM ·

Some online training offered by Uniting for Neurodiverse children 😀

CWS Frank ND series overview Aug-Oct FINAL.pdf · version 1
PDF

Susie Cutlack and 1 other

1 Share

Susie Cutlack
Thanks for sharing Jodes, love ya work 😉 1

9 mos Love Reply More

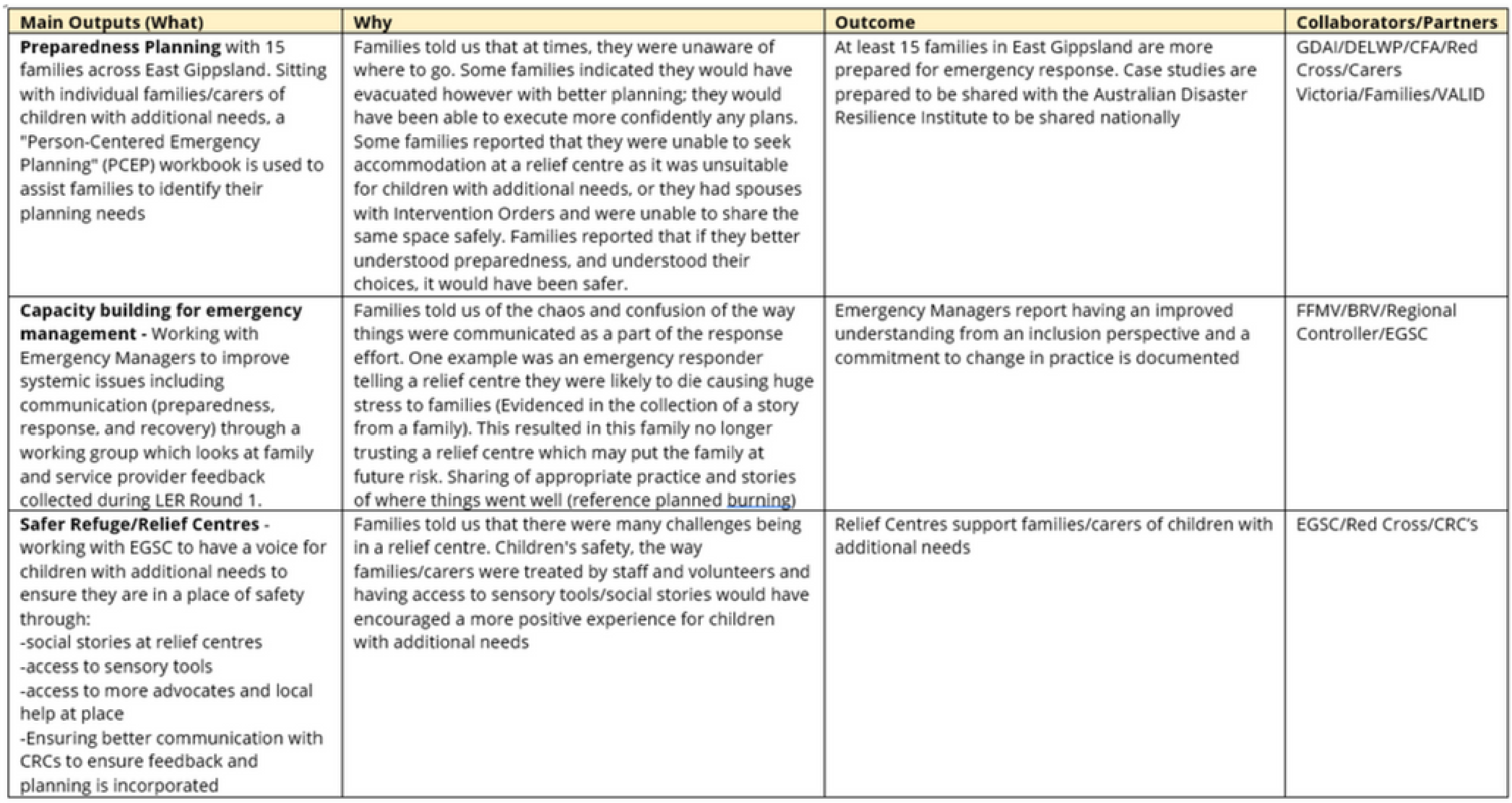
You replied · 1 reply

Flower Grace
Hi I'm Autistic and ADHD and was once a child. If you have any questions I'm here.

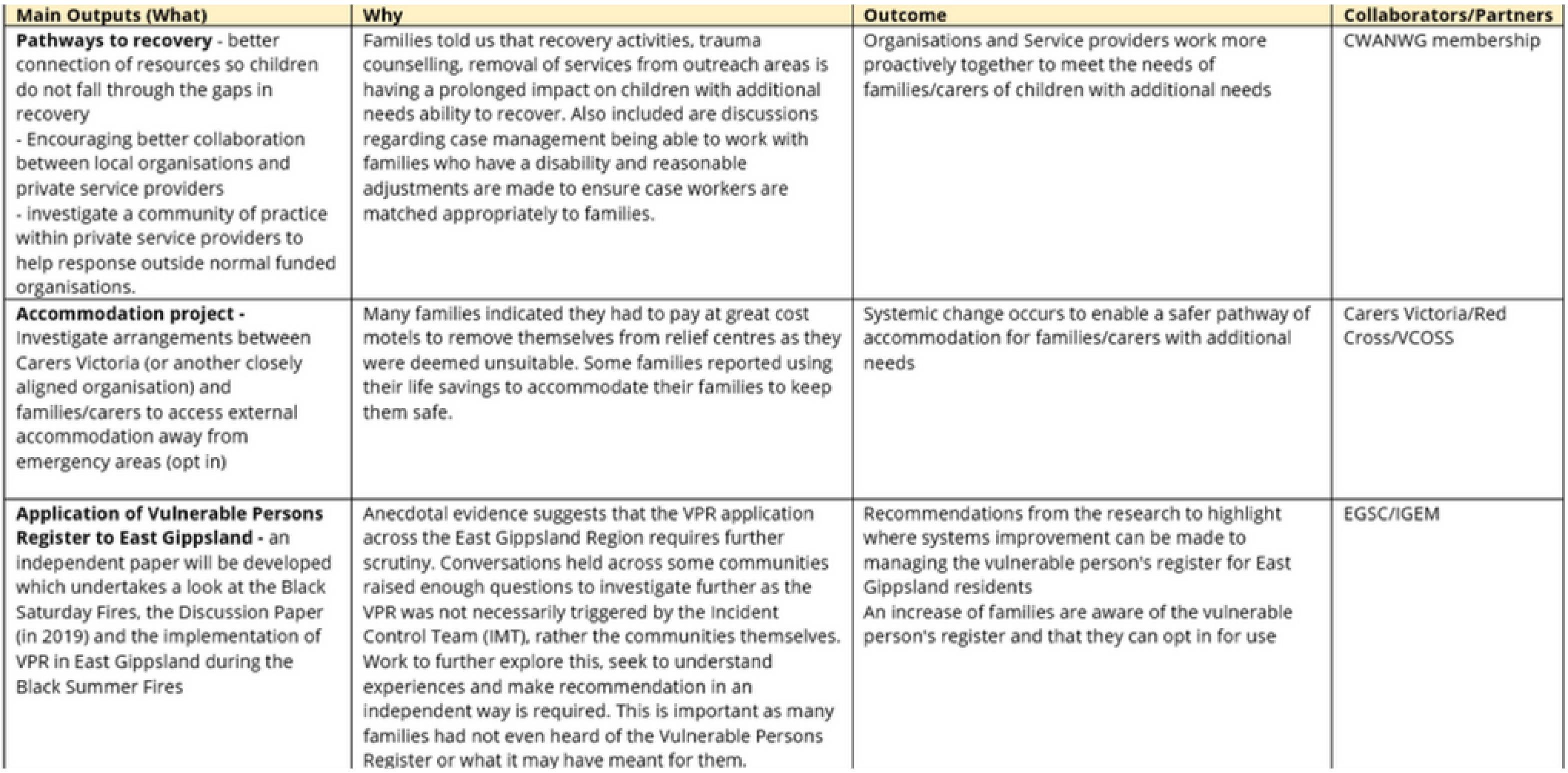
9 mos Like Reply More

Still to investigate:

Further work is still required to continue to build resilience. The Emergency Management Discussion Paper highlights the following priority areas which funding has been sought and approved:



Main Outputs (What)	Why	Outcome	Collaborators/Partners
Preparedness Planning with 15 families across East Gippsland. Sitting with individual families/carers of children with additional needs, a "Person-Centered Emergency Planning" (PCEP) workbook is used to assist families to identify their planning needs	Families told us that at times, they were unaware of where to go. Some families indicated they would have evacuated however with better planning; they would have been able to execute more confidently any plans. Some families reported that they were unable to seek accommodation at a relief centre as it was unsuitable for children with additional needs, or they had spouses with Intervention Orders and were unable to share the same space safely. Families reported that if they better understood preparedness, and understood their choices, it would have been safer.	At least 15 families in East Gippsland are more prepared for emergency response. Case studies are prepared to be shared with the Australian Disaster Resilience Institute to be shared nationally	GDAI/DELWP/CFA/Red Cross/Carers Victoria/Families/VALID
Capacity building for emergency management - Working with Emergency Managers to improve systemic issues including communication (preparedness, response, and recovery) through a working group which looks at family and service provider feedback collected during LER Round 1.	Families told us of the chaos and confusion of the way things were communicated as a part of the response effort. One example was an emergency responder telling a relief centre they were likely to die causing huge stress to families (Evidenced in the collection of a story from a family). This resulted in this family no longer trusting a relief centre which may put the family at future risk. Sharing of appropriate practice and stories of where things went well (reference planned burning)	Emergency Managers report having an improved understanding from an inclusion perspective and a commitment to change in practice is documented	FFMV/BRV/Regional Controller/EGSC
Safer Refuge/Relief Centres - working with EGSC to have a voice for children with additional needs to ensure they are in a place of safety through: -social stories at relief centres -access to sensory tools -access to more advocates and local help at place -Ensuring better communication with CRCs to ensure feedback and planning is incorporated	Families told us that there were many challenges being in a relief centre. Children's safety, the way families/carers were treated by staff and volunteers and having access to sensory tools/social stories would have encouraged a more positive experience for children with additional needs	Relief Centres support families/carers of children with additional needs	EGSC/Red Cross/CRC's



Main Outputs (What)	Why	Outcome	Collaborators/Partners
Pathways to recovery - better connection of resources so children do not fall through the gaps in recovery - Encouraging better collaboration between local organisations and private service providers - investigate a community of practice within private service providers to help response outside normal funded organisations.	Families told us that recovery activities, trauma counselling, removal of services from outreach areas is having a prolonged impact on children with additional needs ability to recover. Also included are discussions regarding case management being able to work with families who have a disability and reasonable adjustments are made to ensure case workers are matched appropriately to families.	Organisations and Service providers work more proactively together to meet the needs of families/carers of children with additional needs	CWANWG membership
Accommodation project - Investigate arrangements between Carers Victoria (or another closely aligned organisation) and families/carers to access external accommodation away from emergency areas (opt in)	Many families indicated they had to pay at great cost motels to remove themselves from relief centres as they were deemed unsuitable. Some families reported using their life savings to accommodate their families to keep them safe.	Systemic change occurs to enable a safer pathway of accommodation for families/carers with additional needs	Carers Victoria/Red Cross/VCOSS
Application of Vulnerable Persons Register to East Gippsland - an independent paper will be developed which undertakes a look at the Black Saturday Fires, the Discussion Paper (in 2019) and the implementation of VPR in East Gippsland during the Black Summer Fires	Anecdotal evidence suggests that the VPR application across the East Gippsland Region requires further scrutiny. Conversations held across some communities raised enough questions to investigate further as the VPR was not necessarily triggered by the Incident Control Team (IMT), rather the communities themselves. Work to further explore this, seek to understand experiences and make recommendation in an independent way is required. This is important as many families had not even heard of the Vulnerable Persons Register or what it may have meant for them.	Recommendations from the research to highlight where systems improvement can be made to managing the vulnerable person's register for East Gippsland residents An increase of families are aware of the vulnerable person's register and that they can opt in for use	EGSC/IGEM

Still to investigate:

Other areas for further investigation which complies with the list of priorities projects include:

- **Diagnostic Pathways** document - an opportunity to provide clear guidance for families/carers on pathways to diagnosis in East Gippsland
- Annual review of the **One Stop School Shop**
- **NDIS Workshops** - a series of workshops run within East Gippsland to share information about Access, Planning and Implementation of plans
- Continuation and expansion of **Sensitive Santa**

What did we learn?

- Recovery is different for each individual. Some families were interested more in education and that their child was struggling to re-integrate into a school environment (post fires and through COVID), some families/carers struggled for supports for their children and continue to do so. Some families/carers received help from case managers that were not experienced in disability and some families received less than acceptable treatment in relief centres. Each family/carer's story was different however themes have been strongly identified through Tables 3 & 4 and throughout various evaluations undertaken on each project area.

- Evaluations, social stories and guidelines have been well received when circulated within community. The documents have met the needs of the families/carers and also created more interest within communities that would not have otherwise been reached. Feedback received has been extremely positive and met the needs of community.

- The presence of the **Children with Additional Needs Working Group** needs to continue and be further advertised within service providers, organisational networks and families. A concentrated media campaign to further promote the CWANWG should be considered across 2022 and 2023 and continue to share the voices of the East Gippsland community.

Case Study
Gabby & Arthur

Gabby lives in a very small remote area of East Gippsland where the population is less than 50. Gabby lives with her son Arthur who is 16 years old and has Downs Syndrome and other co-diagnosis.

Gabby and Arthur's experience of the 19/20 bushfires was significant.

Gabby had done her best to clear her property and become 'fire ready'. She slashed the paddocks and cleaned up the best she was physically able.

Gabby and Arthur left her home to stay in Melbourne with her son at her family's insistence at the end of December 2019. They ended up being in Melbourne for four weeks.

The day after the fires hit their area, they were informed that they had lost their home. Gabby and Arthur were understandably devastated. Gabby felt a strong sense of grief and was really worried as they couldn't afford insurances. Gabby and her son were inundated with donated goods as the word spread throughout the family's networks in Melbourne which Gabby and Arthur were very grateful for.

Within 24 hours, Gabby was told by a neighbour that her home had survived. The feeling of grief turned to "survivors' guilt" and mental fatigue ensued. Knowing that other families had lost their homes in the area was devastating to the close-knit community. Arthur's dad also lost his home in the fires.

The effect on Arthur due to the fires has been profound. Despite requests from Gabby, Arthur (who is non-verbal) has not received any formal trauma counselling.

He was also refused participation to several activities being run in other towns due to the lack of support workers. Gabby was told that Arthur had to have a support worker with him to attend. This meant that any wellbeing recovery in nearby communities was restricted due to not being able to access a support worker.

Gabby was allocated a case manager through a local organisation who has been a good resource for Gabby. While she is still waiting on some things, she indicated that the worker was 'out of her depth' when dealing with disability.

Gabby has noticed that Arthur's aggression and anger has increased since the events of the fires and then lockdown. He has struggled with the loss of his dad's home and has further regressed in his ability to socialise. She has recorded these differences with the NDIS during her most recent review.

Case Study
Gabby & Arthur

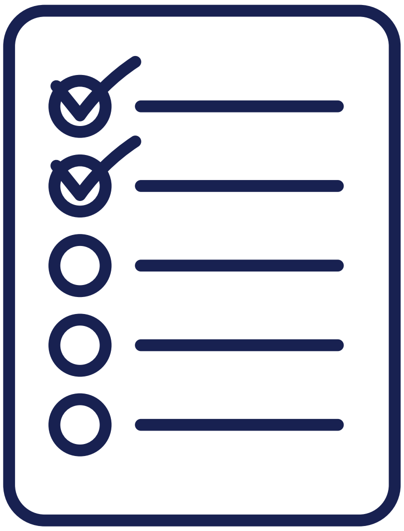
Almost 18 months after the fires and COVID, Gabby has indicated that there has been a lack of understanding about their situation by the NDIS. Gabby was told “you have had two years to get supports in place, why hasn’t this happened?” Gabby said that due to their location, there just are not the services that are available to help her and her son. Their NDIS planner then said “why don’t you move to be closer to supports then?”. This was very upsetting for Gabby. She owns her home and moving to a different location is not an option for several reasons. Gabby is still upset by these comments and believes it is not for lack of trying those supports are available to help Arthur.

Gabby is looking for trauma counselling that is done face to face because Arthur does not do too well online. He only attends school once a week (2 hours away) as the local schools are not equipped to meet his needs (or so they have advised the family).

Lessons learned

If Gabby experienced a fire situation again, her needs would be to:

- Have a sprinkler system available to save her home
- A bunker built so she felt safe
- Consider a safer last minute plan



Case Study

Georgia, Maisie and Pearl

Georgia, Maisie (8 years old and has Level 3 ASD) and her sister Pearl (7 years old and has Level 2 ASD) live in a remote area of East Gippsland.
Georgia noticed some differences and behaviours that were not making sense early on and raised them with the Maternal Child Health Nurse (MCHN) and was signposted to a paediatrician in a bigger town as well as an Occupational Therapist to assist with strategies to help the children and her as a mum.

When Maisie attended the local kinder, Georgia determined that the teacher was not equipped to manage a child with additional needs and did not accept the official diagnosis of Maisie. Statements like “there is no problem with Maisie” and “we shouldn’t put Maisie in a box” were inconsistent with Georgia’s expectations of kinder. Georgia moved Maisie to another kinder and made the drive several times a week where Maisie’s needs were acknowledged and accepted. Georgia advises that she felt well supported and had a ‘good collaborative’ team around her and her children.

Early transition into school went well for Maisie and while managing the school transition, Pearl was also diagnosed with Level 2 ASD. Both children struggle with travelling and due to the difficulties, the children presented, the diagnoses have added major stress to the relationship with her partner. Georgia has also had to spend a lot of time “re-training teachers” at the beginning of each school year and would like to see more effort being placed on transitions between teachers.

Living in a very small community, Georgia struggles with social isolation and the stigma around having small children with additional needs.

Georgia would like to see more inclusive activities for her children to attend. While both are on NDIS plans, the family are struggling to secure a speech therapist and require further help to understand the NDIS plans to help her children.

During the 19/20 bushfires, Georgia’s community was deeply affected. Georgia said that all the roads were shut, and the town was ‘locked in’. Their first thought was to stay in the home however there were fires all around her community.

Georgia and her girls relocated to a local refuge area and stayed there with her cousin and their three children. Georgia recalls the police who were at the refuge area. They were not from the area and clearly had never experienced anything like what was happening.
The police said “*this place is going to catch on fire. When it does, everyone needs to move to the hallway. People will be burning and will be getting burnt. If we have to move outside, people will probably get burnt outside”.*

Case Study

Georgia, Maisie and Pearl

These statements were understandably terrifying for Georgia and her daughters. After hearing that from the police, she thought she and her children were going to die. Her two children were asking whether they were going to die, and their thoughts went to their friends in neighbouring communities. After the wind changed, it took families many hours to calm after being so panicked by the police's actions and communication.

The wind ended up changing to the advantage of the community that day. The family along with others were allowed to return home, however were faced with no food or electricity for days. The only way they were able to reach the outside world was driving their cars following a convoy and Georgia was desperately worried about her partner, who was defending other properties including their business. They were advised that they would die if they stayed so they made it out through the convoy some days later.

Georgia's reflections are:

- It was craziness about who received support in the area and who didn't.
- The silence of the bush after the event was haunting.
- None of the services she was receiving phoned her to see if she and her children were okay.
- It was very hard to see the police and other supports leaving the town every day to safety when they were not allowed to move.
- Georgia is still working through the terror she experienced that day, and subsequent days.
- Georgia would like to ensure that her community has a building that is going to be safe so she can care for her children.
- Post fire, she would like only one point of contact. The days were so hazy at times, she forgot who had called and what they had promised. One point of contact would help immensely to liaise between the family and services.
- Social stories should be made available to families – not just during the emergency but also for planned burning. Georgia would like to be able to share that with her children. The planned burns that occurred in 20/21 were very hard and triggered her and her children.
- Social stories at refuge areas and relief centres that are specific to those areas to help children adjust.
- Families should be offered counselling, not just as individuals.

Case Study

Tammy, Glenn, Samuel and Prue

The fires started to affect us in about October/November as a result of my partner Glenn being a member of emergency services. He was deployed extensively throughout our area and was barely home. When I think about what happened, we are still recovering to this day.
This family live in a small East Gippsland community in the direct line of fires. They were directly impacted by the fires and homes along their street were also lost.

Prue, Samuel and mum Tammy left two nights before fire came through their area. Out of all their extended family, they were the only ones who made the decision to go to the closest town to ‘hang out’. This in itself caused stress as the extended family ‘teased’ us by seeking refuge through the day in another town and her family also kept saying she was ‘going too early’.

Tammy’s son Samuel is autistic and this meant that Tammy was keen to ensure the children were comfortable with being ‘transitioned’ if and when the time came to evacuate. Tammy had also made the decision that while being in ‘town’, she could assess when it was time to stay knowing their property was at risk and they could ‘evacuate’ with lots of time.

The time came to fully evacuate. Tammy reassured her children that they were staying with friends just in case the road became ‘cut off’ and would be closer to groceries if needed. Tammy also encouraged both children to grab things that they would miss if they were in town.

During the night of the fire front, the family found out that the house made it but everything else was gone. Tammy told the children the house was there and went out to have a look as soon as it was safe. Both Tammy and Glenn met at the property and took many photos and showed the children what the property looked like before they saw it the following day. The idea that things had changed from their ‘normal’ was very likely to be overwhelming for both.

The following day, the whole family made it to the property. Both children had a very physical reaction and it was clear their emotions were very confused. "I don’t know whether I’m sad or happy".

Case Study

As a family, the decision was made to move from the home they were staying at which proved to be hugely stressful at the time. While Tammy and the children were at their friends, they were able to keep on top of 'normal' things like meals, washing and communication. When the family moved from that environment, more pressure was placed on Tammy due to starting from scratch. Tammy says "while it seems trivial, not even the basics were in a pantry and there wasn't much space in the cabin we were staying at. The accommodation was fabulous but it was much harder and more lonely on our own. I had to start every meal from scratch and there wasn't a lot of storage for longer stays." My partner, due to his emergency response role came and went and it put a lot of strain on us as a partnership.

Within a week, the town we were staying in also received evacuation orders meaning we ended up further towards the Latrobe Valley with other family members for a few days. It was never going to be sustainable. It came to the point where we wanted to go home and camp. There was no electricity at home, but the children were keen to go home. They just wanted to enjoy the Christmas presents that they had been given. The day we decided to come back our car was running. Prue was sitting in the car and Samuel had absconded with stress. Every time the family got closer to him; he ran away into the backstreets of an unknown town. We had to stop following him so he could come home. We know now that he was too scared to come home because he didn't want to get stuck in another fire. He was scared to come home to a generator. He was scared because it smelt different.

We ended up buying a generator and camped at home. It was good to be home but in the same breath, it was terrible.

I look back now, and we shouldn't have gone back when we did. It was too dangerous. In hindsight, we were living in a weatherboard building and it was probably really unsafe for a whole bunch of reasons. We lived in our home with a generator for three weeks. We managed a trip to Melbourne but the whole time we were there, we just wanted to be home.
In terms of the kids, they had already been suicidal before the fires. We had a referral to a paediatrician in December (but had to decline due to fires), then followed up again in March and got in straight away. Our children's mental health has been up and down since and we are trying to actively engage in recovery as a community, it's still hard.

When Tammy reflects now, she is annoyed because a lot of organisations and education were pushing for recovery programs and children's emotional programs for all of 2020. "**As a family, we kept saying our children are not ready, its too early, we are in COVID, we are not where you think we are. It needs to wait.**" They all kept trying to push it anyway because it was about spending money that was given through grants. The money flowing through is all time bound, it needs to be more flexible.

Just in the last 3 weeks, Prue has pulled out some of the bushfire books. She won't talk more broadly about it with her parents. This is the first time since the fires (Oct 2021) that Prue has engaged, and she wants to do it through books.

Case Study

Tammy's reflections:

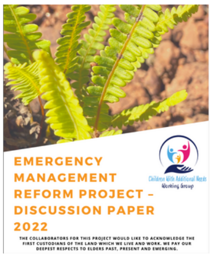
- Our family wasn't eligible for anything because we didn't lose a shed. We lost everything else including play equipment and garden, but we didn't lose 'infrastructure'. That removed us for a lot of grants and opportunities.
- Because of the system, things people registered for in the first week post fire, opportunities are still flowing through to them now. Those 'lists' are still being used. If you didn't register, you don't get access to things. Right now, we need access but because we were not on an original 'list' or registered for particular things, we are still missing out. This seems really unfair.
- While we had a case manager, Tammy ended up doing most of recovery by herself because the case manager was very inconsistent. In the end, it was much easier to do it alone.
- We need recovery information to come through now. Now is the time for checking in with families. Ask "what's surfacing for you now". Provide opportunities for webinars, record something so that families can watch in their own time. Mental health for children with additional needs. Ideas of things to do that can help. Circulate more broadly. Get the communications with community right.
- Need to be asking more questions of the CRC's of how to include people with disability (and their families and carers) into their planning.
- It's really difficult to do evacuation and emergency response when you have a partner in the emergency services out fighting the fires.
- We need more local disability information instead of "your life is really shit – we are not sure what to do with you". Someone that can help people in recovery fill out the forms for you, even eightenn months on. So much has slipped with COVID and home-schooling. We can barely function.
- Having access to social stories and information. Having an allied health group to continually work with and check in with families to see where their needs are as a part of recovery rather than individual therapists. It needs to be part of recovery so our children can get on with their therapy.
- Introducing psychology through animal therapy.
- More communication about what's still available through BRV hubs with examples that might be relevant to us. Use examples to capture and reflect families' different scenarios.
- We need to pay more attention to minority groups now.

Next Steps

The key outcome of this project was to ask families/carers about their experiences through the Black Summer Fires and into recovery. There were no 'right or wrong' answers, this project working through what happened, what needs to continue and what can be done better. As outlined in the Achievements section of this report, a number of key opportunities like social stories for Planned Burning and a recovery activity (Sensitive Santa) were offered through the project life. While unexpected outputs, they were deeply valued by community members.

Implement the Emergency Management Reform Project

The Emergency Management Reform Project has six sub projects to be implemented over the next 12 months.



EMERGENCY MANAGEMENT REFORM PROJECT – DISCUSSION PAPER 2022

Children With Additional Needs Working Group

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Fund other projects and initiatives that were raised and determined as priorities

Other projects including NDIS 101 Workshops, review of the One stop school shop and a Diagnostic Pathway document have all been flagged as priority projects by families/carers and the CWANWG.

Integrate and embed future priorities in community and workplan for CWANWG

Work to be undertaken with Community Recovery Committees and key organisations to ensure feedback is embedded in systems, policy and processes. CWAWNG to continue to work through priorities and advocate needs of East Gippsland voices to be heard.

Further Reading and associated supporting documents

- Media and Communications analysis
- Briefing Note to Children's Wellbeing Collective for Information Hub
- ConnectWell Website: https://www.connect-well.com.au/
- Minutes of CWANWG Meetings - to be placed on Information Hub when available
- Monthly Dashboard of CWANWG meetings - to be placed on Information Hub when available
- Memorandum of Understanding - Survey Questions
- CWANWG December 16 2021 Workshop
- NDIS Early Childhood/Early Intervention Pathway Document
- Media Release for Service Provider list
- BRRP Family and Organisational Stories
- School - The Important Stuff
- NDIS 101 Workshop Evaluation
- Emergency Management Reform Project Paper
- Social Story - Planned Burning
- Social Story - COVID Vaccination
- Sensitive Santa 2021 - Evaluation
- CWANWG Service Provider List and Checklist
- PowerPoint presentation covering key highlights of this report and can be delivered by any member of the CWANWG

Key Contact for Project:
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hello@jodiesimpsonconsulting.com.au

If you would like a copy of any report/discussion paper listed above, please contact Jodie directly.