

## Talking about children and family publicly: an internal document for staff

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### Introduction

Child and family partners (CaFPs) are family members who share their personal experiences in order to help us do the best work possible. From our work in this space, we know that our CaFPs have a wide variety of experiences of adversity, some of which have affected them profoundly. We also know that our CaFPs have many unique strengths, capabilities and identities outside of their lived experiences of adversity. We know that in the majority of cases, CaFPs' primary motivation of being involved in our work is to help other families, in the hope that other people have better experiences than their own.

For Emerging Minds, working with CaFPs brings unique richness and value to our work. It adds a dimension that cannot be acquired any other way. It means that Emerging Minds resources are of a higher quality, have greater integrity, are more engaging and accessible, and have a more positive impact on the children and families whose lives we are seeking to improve.

Child and family partners will each differ in what they bring to the task. They may be very experienced partners of Emerging Minds (with or without experience in speaking publicly), or they may be experienced public speakers who don't know much about what we do. They may or may not be feeling apprehensive about doing this work. Therefore, understanding CaFPs and their unique contribution and needs within each context is important.



## Talking publicly

Child and family partners participate in a range of activities in their work with Emerging Minds. At all times, Emerging Minds staff and CaFPs need to be conscious of the potential impact of this work on them. It is always the goal that CaFPs have a positive and rewarding experience when collaborating with us. Most often, CaFPs report that the experience is strengthening, validating, healing and gives a sense of knowing that what they have shared will contribute to helping others. However, we recognise that this work sometimes presents challenges or overwhelming experiences.



With permission, a child and family partner's story may be used in:

- conference presentations
- media appearances
- webinars
- podcasts
- video or audio interviews (either within an e-learning course or more publicly for website or social media use)

Just because a partner has agreed to share their story publicly, does not necessarily mean that they are happy to have it used in all possible formats. It is imperative that CaFPs consent to the exact use of their personal information. The use of consent forms is important to record this, and refer back to when old footage is being reused.

## Process

As an organisation, Emerging Minds has an ethical responsibility to the families we work with. The following process has been developed to address the potential harmful or unintended consequences of this work. This work is collaborative and involves ongoing discussions between Emerging Minds staff and CaFPs. *Emerging Minds' Child and Family Partnership Coordinators are available to support you throughout this process and are happy to assist.*

### 1. The overarching topic and specific task are introduced to the child and family partner

From the start, CaFPs need to be provided with enough context to decide whether they would like to participate in the task. This includes the goal of the project, topic, audience, length of time the material will be available publicly, remuneration, travel required, and what specifically is being asked of them.

All relevant information should be provided to CaFPs both verbally and in writing. Explicit conversations ensure CaFPs have a good understanding of what is being asked of them, and ample opportunity to discuss the task and ask questions. It is important to check that people have understood the invitation and request, information given to them, and to not assume that they understand what is being asked and/or that they will ask if they do not.

When deciding if they wish to be involved, CaFPs also need to be encouraged to consider if this type of activity is the right thing for them to be doing at this time in their lives. Even very experienced and confident CaFPs need to step back from time to time due to their personal circumstances. This may need to be discussed and supported by Emerging Minds staff.

For CaFPs who come from different cultural backgrounds or if English is their second language, staff will need to consult with a Child and Family Partnership Coordinator on the individual's specific needs in relation to culture, communication and understanding. For Aboriginal and Torres Strait Islander Lived Experience Advocates, staff will need to consult with the Senior Cultural Development Officer.

### A note on the length of time material may be available publicly.

When CaFPs are giving consent, we must ask them to assume that once in the public domain, we may not be able to have material removed, although we will always do our best to address any concerns CaFPs bring to us.

Most of our material will be available online for many years. If in the future, people have concerns about their story being public, they are always welcome to contact Emerging Minds where we will work with them to remove it or find a solution to their concerns. However, it is important to note that even if material is removed, we cannot guarantee that it has not been saved somewhere by someone else. Another example is webinar footage, which we may be able to remove from our website, it may not be able to be taken down from the webinar organiser's site.

### Some examples of written invitations to participate include:

- [Information about e-learning for parents](#)
- [Information about e-learning for adult children](#)
- [Video interview invitation letter for an adult](#)
- [Video interview invitation letter for a young person \(over 18\)](#)



## 2. Benefits and implications are discussed

For child and family partners, this work can have challenging implications as well as positive personal outcomes. It is important for staff and CaFPs to have ongoing reflective conversations. Some points to consider:

- Be clear that the purpose of discussing the implications of talking publicly is not to create stigma (in fact, we are reducing stigma), but to protect children and families from being exposed to the stigmatising attitudes and responses that still exist.
- Provide examples of benefits as well as implications (see examples below).
- Remind the family that a range of emotions may be experienced within a positive experience, and that is OK.
- Reiterate the importance of people sharing a diverse range of stories publicly as examples of hope.
- Avoid competition between people's stories, and the underlying hierarchy of adversity (the experience of depression compared to schizophrenia, for example) or emphasising the experience of people with a public profile over other people.
- Keep in mind ways we can aim for a holistic representation: people are more than their adversity.

### Examples of benefits

Working with CaFPs benefits Emerging Minds as it allows us to create engaging, accessible resources of the highest quality.

For CaFPs, there may be many benefits to participation. Some of those benefits, as told to us by previous and existing CaFPs, include:

- The work can be a strengthening, validating and healing process.
- It can help people have their experiences valued and understood, and use them to have a positive impact on Emerging Minds resources.
- It can help people to feel less alone in their experiences and to feel more connected to a 'bigger picture'.
- People may learn new information and skills within the project (e.g. public speaking).
- It may offer a framework for understanding their experiences that they may not otherwise have had. It may help to make things more coherent for them.
- People may feel proud of themselves for what they have achieved.
- The work can be fun!
- It can help people develop agency in their story.
- It may disrupt a negative trajectory and have positive impacts on personal wellbeing.
- It promotes exposure to other people's stories.
- The work may help people to feel hopeful.
- It creates important role models for family, friends, the wider community.
- It may lead to other formal roles in people's lives (e.g. career or advocacy work).
- It acknowledges the expertise of lived experience.

## Examples of implications

One challenge for Emerging Minds is ensuring that we do no harm. This requires careful consideration and collaborative discussions when we are asking CaFPs to speak publicly.

For CaFPs, there are implications to consider when deciding whether sharing their story is the right thing for themselves and their family, including their children. For example, what would happen if a CaFP shares sensitive information publicly and:

- it is seen by children who go to the same school as their children?
- it is seen by extended family members, who may feel some of the information is private?
- it is seen by potential employers of anyone in the family?
- it is posted on social media and receives critical or unkind comments?
- later regrets it? The partner may feel, in retrospect, that they shared too much information, but now it is in the public domain they are unable to take it back.
- their story of adversity becomes their identity?
- professionals who have worked with the family are able to be easily identified?

Quotes from two experienced CaFPs:

*"I have learned to err on the side of anonymity. Even the most innocuous information in the public domain can be a source of later regret."*

*"When I think back about how open I was I worry... these days I wouldn't mention my children specifically and wouldn't use our names I don't think."*

## 3. Options for protecting privacy are discussed and agreed upon

1. Discuss fully with CaFPs what their options are.
2. Once implications have been discussed, consider who needs the protection of anonymity.
3. Together, consider the use of pseudonyms, not just for children, but for everyone in the story.
4. Together, consider ways to deidentify stories about children, family and third parties (such as services, health professionals, schools, and so on).
5. Discuss options for anonymity (see examples below). CaFPs are likely to make different choices about levels of anonymity and privacy required at different points in their lives.
6. Support CaFPs to consider what they will and won't say publicly about their children and family. Consider their current situation, but importantly also the future.
7. Consider ways of building on the work that continues to share people's stories in deidentified ways (e.g. a co-authored product).

## Mechanisms for protecting privacy will vary per project, but examples include:

- audio-only webinar
- video webinar with strong use of pseudonyms and deidentified stories
- webinar speaking generally or reflecting on a case study, rather than sharing the family's own story
- audio-only interview
- audio interview that is portrayed by an actor in the final product
- video interview with strong use of pseudonyms and deidentified stories
- video interview filming the back of the interviewees head and the face of the interviewer
- print media interview using pseudonyms and no photos.

#### 4. Any permission required from family members, including children, is discussed and agreed upon

Together, consider if CaFPs need to seek permission from their children and family prior to being involved in the project. Consider that children and adolescents, due to their age and life experience, should be considered unable to give formal consent, however their wishes can still be sought.

Be mindful of family members who the CaFP may be estranged from or who, for other reasons may not be able to take part in conversations around consent. For example, the conversation may be too confronting, cause distress or damage a relationship. See point 3 above about mechanisms for protecting privacy as needed.

##### Example of this process from a child and family partner perspective

“I think talk to your children and family about the project, discuss the implications then get their ideas and consent to use their story, if at all, and then make a decision about whether or not anonymity should be in place. My experience says that at all times ensure anonymity. I do not think children should have full responsibility for that decision.

When one of my children was 16 years old she was quite altruistic about sharing her and her family’s story; wanting to help others and combat prejudice head-on. Later on, as a young professional she has expressed relief that her privacy had been maintained because of the long-term nature of information on websites and the potential for her to have been Googled. Now, she prefers that identifying markers such as her specific professional role not be identified.”

#### 5. Social media use is discussed and agreed upon

Together, consider how both CaFPs and Emerging Minds will (and won’t) use social media to promote or discuss the project being undertaken. Inform the CaFP of EM social media platforms and promotion processes our Communications team has described below so their awareness is heightened. This is to protect the privacy of the CaFP and their family, especially children. If possible, plan Emerging Minds social media posts ahead of time after discussing the following questions:

- Will the CaFP’s name and photo be used in social media posts or not? Seek specific consent for this.
- If Emerging Minds makes social media posts relating to the project, will the CaFP share these and state their involvement in it?
- Will they ask their family members to share and comment on, or not share and comment on, these posts?

##### Example of how social media may cause harm

Emerging Minds asks a parent to be involved in a webinar talking about their experience of seeking support for their child’s mental health.

Emerging Minds advertises the webinar on Facebook, not naming the parent in order to protect the family’s privacy. The parent wishes to promote the work of Emerging Minds and shares the post stating they will be involved. The child is now able to be identified by anyone who sees the post shared by their parent.

Emerging Minds also promotes the webinar on LinkedIn. A family member congratulates the parent for being involved in the webinar. This well-meaning, proud, supportive and encouraging family member inadvertently identifies the parent and therefore the child with mental health difficulties in a public professional networking space.

There are clear implications in these examples for the child and their family. It is also possible that professionals involved in the care of the child (who may be mentioned in the webinar and may not have provided optimal support) may also be able to be publicly identified.



## A note from our Communications team

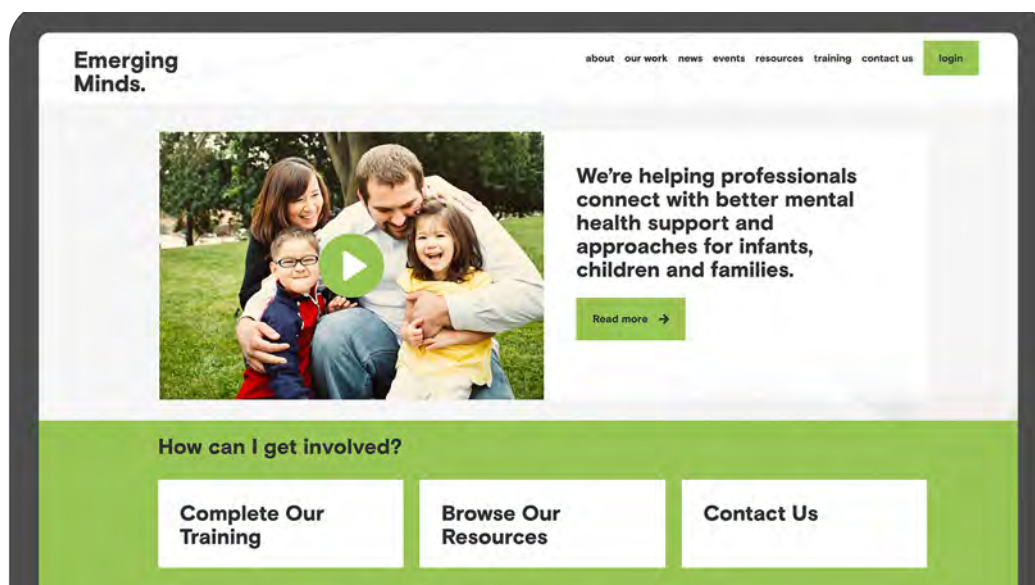
Our online footprint is wide, and constantly growing! It's really important for our CaFPs to be aware of this. In general, for a typical resource we will:

- promote it in our newsletter (distributed to approximately 53,000 people)
- upload it to our website; and
- feature it on Facebook, Twitter and LinkedIn.

Resources are also re-promoted at regular intervals throughout the calendar year. Our delivery partners (organisations we work with) will also cross promote, so it's possible, depending on the resource, that AIFS, PRC and CFCA will feature it in their newsletters and on their social platforms, and anything GP-related will be promoted by the RACGP through their networks too. Plus, there are a raft of other newsletters from a growing list of organisations sharing our work around the country.

Our webinars are a good example of how we work online. Because they are produced with partner organisations, they are also promoted on their social networks and newsletters as well as ours. And they are promoted multiple times – a few weeks before the webinar to drive registrations, close to the event, on the day of the event, and post-event once the recording is available. They will also be re-shared if the subject matter ties into another product release or an awareness week/day.

We are always happy to chat about our plans for promoting a resource and answer any questions our CaFPs may have.



## 6. Ensuring what is agreed is carried out

Allocate a lead staff member who is responsible for overseeing this work. Ensure that all staff involved understand that although the workload may be shared, the lead staff member should be consulted and updated as they hold all of the knowledge as it relates to the CaFP's situation and decisions.

Project staff should communicate decisions with other Emerging Minds staff as appropriate. Consider if you need to communicate with the:

- webinar provider
- e-learning developer/author
- line manager or director
- Child and Family Partnership Coordinator
- Senior Cultural Development Officer
- Communications team (especially regarding social media).

## Example

Emerging Minds invites a couple to be involved in a filmed interview, to be used in an e-learning course and a promotional video. The lead staff member introduces the project including consent requirements and the issues of disclosure and anonymity. The parents are committed to reducing stigma and being public about their experience. They decide they do not want any particular mechanisms employed to protect their privacy (i.e. they'll be filmed front on with their real names in superscript).

As the conversation continues, they talk of a significant experience that clearly illustrates a key message. It includes the role of their 16-year-old son in support of his younger 9-year-old brother who has a disability. The lead explores the issue of the children's privacy and future potential reach/dissemination of the material. The parents and the lead both recognise the example is a very potent one but understands that this may have immediate implications for the older child, who is highly involved in a local community volunteer group. They consult him and he asks if it can be done in such a way that he isn't identifiable (i.e. no mention of gender/name/age etc.) An agreement is reached, and the lead informs the staff involved in filming about the agreed family consent restriction.

The lead has planned to be present for the filming, but has to take unexpected leave. On filming day, the son's experience of watching the filming quickly results in him changing his mind about anonymity. He is inspired by the process as he listens to his parents. While he is clear he doesn't want to be interviewed/filmed himself, he indicates he feels it would be better if identifying details weren't avoided. EM filming staff, the parents and son discuss and agree to re-shoot a response to one question and then proceed similarly for the rest of the shoot.

When the lead is later reviewing the film transcripts, he realises that anonymity hasn't been maintained and seeks clarification.

While consent of the older child has been handled transparently and respectfully there are still clear implications for the younger child that the change on filming day hasn't taken into account. When reminded of the initial discussion with the lead about privacy and the written consent, reference to both children, the parents realise that in being supportive and respecting their eldest son's wishes, they have assumed consent for the 9-year-old without considering the implications for him.

## 7. Relationships are nurtured

Child and family partners consistently report that positive relationships are a vital component of their engagement with Emerging Minds. Creating good relationships is fundamental to ethical conduct in this space and ensures that CaFPs are valued, safe and supported. These relationships also enable CaFPs to communicate what is happening in their lives and you can respond accordingly. Relationships with staff require a genuine commitment of time and curiosity beyond focussing on a person's experiences of adversity.

### Right before the event

If you won't be seeing the CaFP face-to-face, then it will be especially important that you make phone contact beforehand to ensure they feel well-prepared and to answer any questions they have.

If you will be seeing them face-to-face then allow time to spend with them beforehand. Share a tea/coffee, relax into the situation, allow for a toilet stop, and so on. Working with a CaFP is quite different to working with a practitioner.

### After the event

If you won't be seeing the CaFP face-to-face, then a phone call to check-in with them shortly after the event is critical. The purpose of this call is to offer an opportunity for them to reflect, and for you to respond to their experience of the process.

### Do

● **thank** them for their valued contribution

● **find out how** it went from their perspective

● **hear**

- any reflections they have had since
- any feedback about how the process went well or could be improved
- in what ways, if any, their involvement was useful for them and their family
- if anything unhelpful for them or their family came about as a result of the work. What might Emerging Minds have been able to do to lessen the likelihood of it happening, or to lessen the effect on them?

- **let them know** the next steps for the project and discuss any future involvement they may have in this project or others

#### Also

- **ensure payment** for their time and expenses has been organised
- ensure they know they can contact Emerging Minds to discuss any of the above in the future
- confirm how and when you will be in touch about the outcome of their work (e.g. informing them when a resource is launched)
- Have the above conversation over a tea/coffee or at lunch/dinner later that day if possible. CaFPs have reported that it can be helpful to have some time between the work and the check-in conversation, as it allows for some reflection.

Know that if you make the time to have a meal with a CaFP then the expense will be paid for by Emerging Minds (as per the meal allowance form) and your time may be entered on your timesheet if out of hours.

#### Stepping back

Remember that some partners may need to step back from sharing or reflecting on their personal experiences. Good relationships can help you to find other ways to involve them (which may require skill development first); or for partners ready to move on, help identify other opportunities and projects that may interest them.

#### Example from a child and family partner

*“Sometimes engagement or participation will be planned well in advance, and later, the date may coincide with unexpected family events that make the original topic particularly sensitive and quite possibly inappropriate or overwhelming to talk about.*

*More specifically, for me this occurred when I was lined up by another organisation to make a lived experience presentation at a conference, which coincided with the time my father was dying. This was of course pertinent; the presentation was about me being his child, the child of a parent with a severe mental illness. I went ahead and delivered the talk but found that retrieving memories from the past was overwhelmingly distressing at that time; the talk went very badly from my perspective.*

*Being in a supportive partnership relationship would have given me the opportunity to reflect that giving the talk at that point was not a sensible idea and to withdraw.”*

## 8. Capacity-building is nurtured

Capacity-building is another core element of high-quality family partnership work. It is important that the benefits of partnerships are reciprocal, and that children and families are not exploited.

Consider how you may offer CaFPs opportunities to develop new knowledge and skills throughout their involvement. See below for some examples you may be able to consider.



### Examples of capacity-building include:

- Supporting a CaFP to develop public speaking skills within the project.
- Supporting a CaFP to learn about the project they are involved in.
- Providing a certificate or reference regarding their contribution as a partner, including the knowledge and skills they gained, and framed in general terms which are appealing to future employers.
- Providing some wording about the project and their participation that can be cited in resumes, biographies, etc.
- Considering how you could give people opportunities to expand their skills in other areas and develop their confidence.
- Offering monetary grants to help the CaFP to:
  - develop skills (e.g. to attend a workshop or conference, develop writing skills, develop employment skills or attend a governance course)
  - write an article or narrative for publication (this may involve co-authoring or supporting them to independently author and seek publication).
- Offering monetary grants and practical support to prepare and present at relevant conferences (this may be co-presenting or presenting independently or as part of a symposium).
- Organising workshops, such as media training or public speaking.
- Where appropriate, inviting CaFPs to join staff training sessions. This would not only facilitate skill development but would also help to equalise relationships between staff and participants.
- Offering participants support in formulating their own personal narrative – a coherent, authentic text of their own lived experience that they could share with their colleagues and beyond.
- Co-facilitation – when Emerging Minds is providing training to staff, how can you provide training and support to family members so they can be effective and valuable co-facilitators of your training?
- Considering what you can provide to people at a low cost. For example, can you support partners to develop and tell their personal stories? ([Speaking our Minds](#) is a useful tool) Or can you enable people to set up their own groups to achieve goals that may not fit within Emerging Minds funded deliverables? ([Our Consumer Place](#) is a useful resource)

## 9. Child and family partner wellbeing is a priority

The wellbeing of CaFPs must always come first. Discussions concerning wellbeing should occur at every stage of the process and include:

- acknowledgment of CaFPs' generosity and the gift of their experiences and wisdom as given to others
- CaFPs' informal and formal supports, and what they would do if they feel triggered or in need of support when working with Emerging Minds
- details of which staff member/s they should call if they are in need of support. This will usually be one of the Child and Family Partnership Coordinators, but it could be other staff if agreed
- information on self-care – CaFPs should be given a copy of our [Self-care tip sheet](#)
- consideration of people's personal circumstances when they are speaking publicly. How are they feeling today? Connect with them and check in with them about this
- a back-up plan if the CaFP wants to withdraw during the process or at the last minute
- mechanisms for reflection for CaFPs, and reflection and quality improvement for staff
- consideration of Emerging Minds' responsibility to do no harm while respecting and supporting CaFPs' right to
- make decisions about what is best for them and their family (often referred to as the dignity of risk-taking)

## 10. Informed consent is sought

The final step of the process is to ensure that the consent form is signed by all parties, and that information regarding any particular consent decisions has been recorded on the form. You can download a copy of the consent form [here](#).

### Checklist

Task	Complete Y/N	Notes
1. The overarching topic and specific task have been introduced to the child and family partner.		
2. Benefits and implications have been discussed.		
3. Options for protecting privacy have been discussed and agreed upon.		
4. Any permission required from family members, including children, has been discussed and agreed upon.		
5. The use of social media has been discussed and agreed upon.		
6. Emerging Minds staff have communicated the above decisions to relevant parties.		
7. Relationships have been nurtured.		
8. Capacity-building has been nurtured.		
9. Plans for CaFP wellbeing have been discussed (including a back up plan for if the partner wishes to withdraw at any point).		
10. Informed consent has been sought. Consent form has been signed.		

### Other ways for families to talk publicly

A child and family partner may decide that they don't not feel comfortable sharing their personal story and experiences publicly, but still want to help. If they prefer, they could contribute by 'drawing on' their experiences to share their knowledge and insights (by speaking in general terms without detailing information about their children or family, or responding to a case study, for example). In this way they are not actually re-telling aspects of their story or sharing personal details about their children and family. This is also a highly-valued way of contributing, and may still bring challenges as different memories and experiences are recalled.

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