

Trauma Informed Care Models and Frameworks in Paediatric Oncology

Volume Two, Ancillary Report – Models





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The Child Cancer Foundation and Author of this report would like to acknowledge and thank Massey Universities Professor Kirsty Ross for peer reviewing this report.

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The NZ Child Cancer Foundation is committed to providing support services for whānau facing childhood cancer. Founded by medical professionals and parents, this charity walks alongside and supports hundreds of whānau each year.

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ISBN Number 978-1-0670625-2-1

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Tō tuāoma timatatanga
Ō kawenga pikau mahi
Ka hāere tonu ia ra, ia ra
Mō ō ratou oranga

Your journey began
With challenges day after day
With integrity and commitment
We support you and your
whānau with empathy



Houston, diagnosed age 3.

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Key Terms and Glossary

Acute Stress Disorder	A diagnosis made in the acute phase that is confirmed if the patient meets criteria for 9 of 14 symptoms.
Acute trauma	Short term response to a traumatic event that usually results in the 'flight/fight' response.
Adverse Childhood Experiences (ACE)	A trauma occurring in childhood including emotional, sexual and physical abuse, neglect, and family dysfunction. Research shows these traumas increase the likelihood of adult disease.
Burnout	Burnout is the cumulative psychological strain and state of exhaustion from working under challenging conditions.
Chronic trauma	Trauma resulting from exposure to stressors that are repetitive or prolonged.
Compassion fatigue	Compassion fatigue is the emotional exhaustion from helping others and can lead to reduced capacity to be empathetic.
Complex trauma	Trauma resulting from multiple overlapping or successive events that may or may not be related.
Dissociation	A mental process where a person disconnects from their thoughts, feelings, memories, behaviour or sense of identity. Usually arises as a reaction to traumatic or painful events.
Hauora	Health, wellbeing.
Historic trauma	Traumatic events that are experienced so broadly that they affect an entire culture (e.g. colonisation, slavery) and is likely experienced over multiple generations.
Kaupapa Māori	Māori ideology, a philosophical doctrine incorporating the knowledge, skills, attitudes and values of Māori communities.
Leukaemia	Leukaemia is the name given to a group of cancers that develop in the bone marrow. Leukaemia develops in blood cells that have undergone a malignant change.
Paediatric Medical Traumatic Stress (PMTS)	A set of psychological and physiological responses of tamariki and their whānau to pain, injury, serious illness, medical procedures and invasive or frightening treatment experiences.
Post Traumatic Stress Disorder (PTSD)	A mental health condition triggered by a traumatic event, either experiencing it or witnessing it in person. Symptoms may include flashbacks, nightmares, and severe anxiety, as well as uncontrollable thoughts about the event.
Post Traumatic Stress Symptoms (PTSS)	Post Traumatic Symptoms that may be present without meeting the full criteria for a diagnosis of PTSD.

Resilience	The protective mechanisms that have the potential to enhance individual recovery after a traumatic event.
Secondary traumatic stress	The emotional stress response experienced by a person who is exposed to the trauma, pain and/or suffering of others. It is an occupational hazard for persons working with traumatised people. Secondary traumatic stress is also known as compassion fatigue and vicarious trauma.
Tamariki	Child or Children.
Tikanga	Correct procedure, custom, habit, lore, method, manner.
Tino Rangatiratanga	Tino Rangatiratanga relates to sovereignty, autonomy, control, self-determination and independence. The notion of Tino Rangatiratanga asserts and reinforces the goal of Kaupapa Māori initiatives, allowing Māori to control their own culture, aspirations and destiny.
Trauma	Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being. ¹
Trauma Informed Approach	A programme, organisation or system that is trauma informed realises the widespread impact of trauma and understands potential paths for recovery; recognises the signs and symptoms of trauma in clients, whānau, staff and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatisation.
Trauma Informed Care (TIC)	Trauma informed care means a programme of care that seeks to avoid re-traumatisation by using a trauma informed approach.
Vicarious resilience	The inspiration drawn from observing others who are experiencing difficult or traumatic circumstances.
Vicarious trauma	Vicarious trauma is the cumulative effect from prolonged exposure to the trauma of others. It involves harmful changes in an individual's personal beliefs, worldview, attitude, and sense of safety.
Whānau	Extended family or family group.

¹ Substance Abuse and Mental Health Services Administration (SAMHSA) Trauma and Justice Strategic Initiative 2012, p.2

Executive Summary

This volume outlines the trauma informed care frameworks and implementation models that were identified in the research of peer-reviewed/published and grey literature² from Aotearoa New Zealand, Australia, United States and the United Kingdom. Refer to Volume One for more detail regarding the research plan. As a result of the research focus, the models found in the academic literature are primarily focused on psychosocial interventions in clinical settings.

Other models on the application of trauma informed approaches and trauma informed care in non-clinical settings have been included in this volume in order to describe information available to support Child Cancer Foundation as it considers its own organisational development.

Most of the models in this Volume build upon or are informed by the work done in 2014, by the Substance Abuse and Mental Health Services Administration (SAMHSA) in the United States. The Trauma informed Care in Behavioural Health Services, Treatment Improvement Protocol Series 57³ (TIP 57) is very pervasive in 'Western' materials in the trauma informed care field, including in the work of the NZ Ministry of Health and Te Pou.

The work undertaken in Aotearoa New Zealand to adapt sound trauma informed practices to the cultural needs of the Aotearoa New Zealand setting is underway with work completed by organisations like the NZ Ministry of Health, Te Pou⁴ and Te Kotahi Research Institute⁵. This work provides helpful foundations for Child Cancer Foundation but does not release the organisation from its obligation to engage with tangata whenua.

Further, the history of colonisation in Aotearoa New Zealand, and its ongoing impacts on Māori and other non-pākehā communities, reminds healthcare service providers that a trauma informed future is not just adapting current services to take account of new science in the treatment of trauma. Instead, it challenges inequitable health service providers to reform and change themselves so that they are credibly re-positioned as thoughtful and inclusive service providers. It is only through this deep reform that organisations can credibly strive to avoid re-traumatisation of the whānau in their care.

This ancillary report should be read in conjunction with Volumes One and Two.

² Grey literature is research and information that is published outside commercial and academic publishing houses. As a consequence it is not usually searchable via standard academic databases and search engines.

³ Substance Abuse and Mental Health Services Administration, 2014, 'Trauma informed Care in Behavioural Health Services, Treatment Improvement Protocol Series 57', HHS Publication No. (SMA) 3-4801, Rockville, MD: US Department of Health.

⁴ Te Pou, Trauma Informed Approach: An update of the literature' 2024.

⁵ Pihama L., Smith L., Cameron N., Nana R. T., Kohu-Morgan H., Skipper H., & Mataka T., 2020, 'He Oranga Ngākau: Māori Approaches to Trauma Informed Care', Te Kotahi Research Institute, Hamilton.

Kimberg's Four C's of TIC

Leigh Kimberg's practical model of care is included in the book 'Trauma Informed Healthcare Approaches'⁶ which seeks to transform care at the level of the carer/patient encounter. It builds on the work completed in the ACE Study and seeks to provide a TIA to all levels of healthcare organisations. This model recognises that the effects of childhood trauma which are at the root of many adult behaviours, conditions and diseases, can present often decades after the traumatic event.

The Kimberg Principles are intended to promote health throughout a trauma informed 'ecosystem'. Their application should be considered a "journey rather than a fixed set of interventions"⁷. In trauma informed systems, respectful approaches that "earn patients and communities trust and cultivate resilience, positive coping strategies, and a sense of control are emphasized."⁸ Practitioners must commitment to ongoing self-reflection and practice. The four C's principles that underpin that practice are: Calm, Contain, Care and Cope.

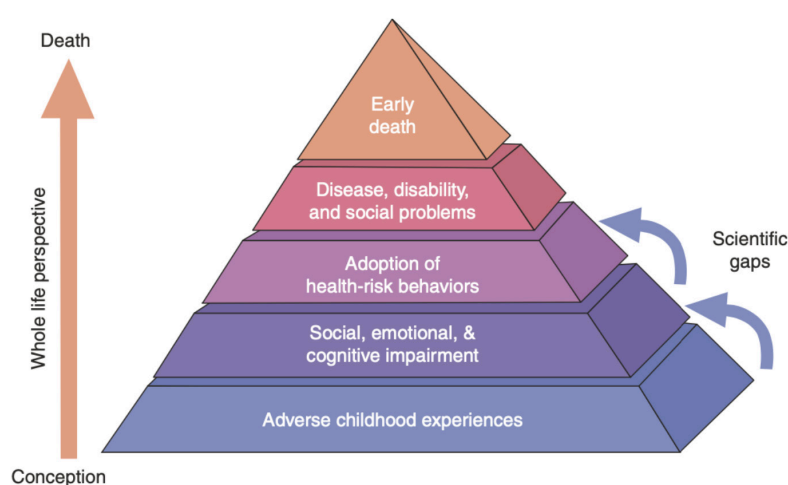


Figure 1: Adverse childhood experience and lifetime health. www.cdc.gov/violenceprevention

Table 1: The Four C's of Trauma Informed Care⁹

Objective	Strategies
Calm Pay attention to how you are feeling when you are caring for the patient. Breathe deeply and calm yourself to model and promote calmness for the patient, yourself, and your co-workers.	Practice calming exercises (deep breathing) with patients
	Cultivate understanding of trauma and its effects to promote a calm, patient attitude toward others (patients and co-workers)
	Re-design healthcare environments, policies, and practices to reduce chaos and promote calmness
	Cultivate understanding of how resilience, justice and equity build peaceful, calm communities and environments

Table continues on next page

⁶ Gerber M. R., (ed) *Trauma informed Healthcare Approaches: A Guide for Primary Care*, Springer, Switzerland, 2019.

⁷ Kimberg op. cit., p. 32.

⁸ Kimberg op. cit., p. 33.

⁹ Kimberg op. cit., p. 34.

Objective		Strategies
Contain	Limit trauma history detail to maintain emotional and physical safety. Provide education, resources, and referrals to trauma-specific care without requiring disclosure of trauma.	Model healthy relationship boundaries and earn trust by behaving reliably
		Monitor patient's emotional and physical responses to education and inquiry about trauma
		Practice calming techniques to help patient (or parent/caregiver) regain composure
		Normalise fear of returning to the healthcare setting where the triggering of a trauma response occurs; invite the patient to share what changes would make visits more tolerable and healing
		Enact healthcare policies and practices that minimise re-traumatisation of patients and staff
Care	Practice self-care and self-compassion while caring for others.	Form multi-disciplinary and multi-sector partnerships that reduce re-traumatisation for patients and staff
		Share messages of support when patients disclose trauma or trauma symptoms
		Normalise and de-stigmatise trauma symptoms and harmful coping behaviours (as common sequelae ¹⁰ of trauma)
		Practice cultural humility
		Adopt practices and policies that minimize and mitigate power differentials to reduce trauma and structural violence
Cope	Emphasize coping skills, positive relationships, and interventions that build resilience.	Enact healthcare policies that promote self-care, compassion, and equity
		Form equitable partnerships to extend CARE into the community
		Enquire about practices that help the patient feel better and more hopeful
		Document a "Coping strategies" list instead of only "Problems Lists" and include patient's own words of wisdom and good self-advice in the "after-visit" summary
		Improve identification and treatment of the mental health, substance use, and other sequelae of trauma
		Connect patients and families with community organisations to increase social support and access to necessary resources
		Promote equity within healthcare organisations, communities, and society

¹⁰ Sequelae means a condition which is the consequence of a previous disease or injury. (Oxford Dictionary).

United States Substance Abuse and Medical Health Services Administration (SAMHSA) Trauma Informed Approach

The SAMHSA approach to trauma informed care is summed up by one simple yet fundamental reframe. Moving from “what is wrong with you” to “what happened to you” quickly reduces shame, guilt and blame. This approach clearly identifies trauma as an experience a person is having, rather than something that they are.

SAMHSA advises that for a programme or organisation to be considered trauma informed, it is not enough to provide trauma informed interventions or services. Instead, an organisation should go further and incorporate trauma informed principles in its culture, policies, procedures and practices. By adapting trauma informed approach holistically SAMSHA advises that the organisation will be able to acknowledge the trauma that staff, volunteers and board members themselves experience, either as part of their own experiences, or by working with clients who share their own trauma.

The SAMHSA approach is grounded in four key assumptions, six principles and ten implementation domains.

Assumptions

1. **Realise** the widespread impact of trauma and understand potential paths for recovery.
2. **Recognise** the signs and reactions of trauma in clients, families, staff, and others involved with the organization.
3. **Respond** by fully integrating knowledge about trauma into policies, procedures, and practices.
4. **Resist** re-traumatisation.

Principles

1. **Safety:** Safety in physical settings and interpersonal interactions.
2. **Trustworthiness and transparency:** Operations are conducted and decisions are made with transparency, consistency, respect, and fairness so as to build and maintain trust.
3. **Peer support:** Support from those with lived experiences of trauma or, in case of children with history of trauma, their family members.
4. **Collaboration and mutuality:** Partnering, levelling power differences between and among staff and clients.
5. **Empowerment, voice, and choice:** Individuals' strengths and experiences are recognised and built upon.
6. **Cultural, historical, and gender issues:** Organisation moves beyond cultural stereotypes and biases.



Figure 2: SAMHSA Practical Guide for implementing a Trauma informed Approach

“For a TIA to flourish, the organisational culture will need to value not only lived expertise but also trauma experiences of a person’s ancestors that continue to affect the client today. TIA begins with cultural humility at all levels – individuals, organisations and systems.”

SAMHSA Practical Guide¹¹

¹¹ Substance Abuse and Mental Health Services Administration, 2023, 'Practical Guide for Implementing a Trauma informed Approach', U.S. Department of Health and Human Services, Publication No. PEP23-06-05-005, P. 10.

Domains of Implementation

SAMHSA's ten implementation domains are:



SAMHSA Implementation Process

1. Planning phase

SAHMSA recommends organisations carry out extensive planning and baseline assessment prior to implementing TIC. Baseline assessment is recommended in order to measure progress in organisational TIA competences. Key planning activities are:

- Conduct a baseline assessment of organisational readiness
- Form an organisational capacity assessment team
- Encourage organisational readiness
- Engage partner organisations and individuals with lived experience
- Select an assessment tool
- Decide on data collection and analysis methods
- Implement the assessment and decide on next steps

2. Implementation phase

The following paragraphs have been excerpted from SAMHSA Practical Guide for Implementing a Trauma informed Approach, Chapters 2 through 4.¹²

Governance and Leadership

All individuals within the organization play a critical role in prioritizing a trauma informed approach. To demonstrate a genuine investment in trauma

informed approach, organisations can:

- Show transparency with organizational operations and decisions, with a goal of building and maintaining trust at all levels, including regular, open communication with staff, partners, clients, and families regarding the organization's trauma informed approach commitment.
- Ensure individuals with trauma histories are in governance and leadership positions and involved in planning (i.e., "levelling of power").
- Identify a "champion" in a position of authority with a dedicated role of instilling trauma informed principles and practices into the organization. This person also can help support staff in promoting and practicing a trauma informed approach.
- Ensure leaders model a trauma informed approach within their organization and encourage individuals at all levels to check one another when actions do not align with a trauma informed approach.

Training and Workforce Development

Implementing a trauma informed approach across organizations and systems involves intentional strategies for recruiting, hiring, training, and retaining both clinical and non-clinical staff. To facilitate this, organizations can:

- Hire a trauma informed workforce.
- Train staff in a trauma informed approach.
- Train non-clinical staff, such as organizational

¹² SAMHSA, *Practical Guide for Implementing a Trauma informed Approach*, 2014, p. 12 – 30.

leadership, administrative personnel, reception staff, and security guards, along with clinical staff.

- Prevent secondary traumatic stress in staff.

Cross Sector Collaboration

A trauma informed approach is most effective in reaching positive outcomes when implemented consistently and collaboratively across various human services sectors. Organizations often focus on offering individual services; however, from a client perspective, multiple systems are engaged and intricately connected in people's lives. If individuals and their families receive trauma informed services through one organization but not others they interact with, trauma informed approach effectiveness is highly reduced. Integrated, collaborative, community-wide, cross sector trauma informed approach implementation is essential.

One way to establish a cross-sector trauma informed approach is to create a trauma informed referral network that includes all service providers within a community or system of care. This network can be achieved through efforts like convening a multi-agency trauma informed approach implementation task force that offers collaborative trauma informed approach training opportunities across the community or inviting clients to serve on advisory boards across agencies.

Another strategy is to establish a community-based learning collaborative. A community-based learning collaborative brings together multiple service-providing agencies within the community with the goal of facilitating implementation of interventions and innovations. This community-level, systemic approach to trauma informed approach implementation increases the likelihood of its sustained and long-term impact.

Financing

Identifying a sustainable financing strategy is necessary to fund a trauma informed approach, including resources for staff training; development of safe facilities; provision of screening, assessment, treatment, and recovery supports; and development of cross-agency collaborations. Traditional payment systems and billing codes often create barriers to implementing a trauma informed approach, since there are few direct reimbursement mechanisms specifically for trauma informed activities. Organizations can use several strategies to address these challenges and maximize financing opportunities:

- Diversify funding streams by using a combination of sources to support trauma informed approach implementation: Potential sources include: public insurance programs, commercial insurance, client self-pay, state and federal grants, and private philanthropy.

- Determine what potential trauma informed approach activities, procedures, staffing, or encounters are covered by funders or payers under current agreements: This process should include cross-referencing with funding options available for trauma informed approach implementation through initiatives or other special programs; that is, certain evidenced-based practices or quality improvement initiatives that may align with trauma informed activities are reimbursable.
- Incorporate trauma informed activities into existing reimbursable services: Organizations can think strategically about how implementation changes made for a trauma informed approach fit into activities that are already provided and billed.
- Consider accountable care models, which provide more incentives for investing in a trauma informed approach by rewarding value over volume: Accountable care depends on coordinated care management and multidisciplinary collaboration, both of which align with a trauma informed approach.

Physical Environment

Within a trauma informed organization, the environment must foster both physical and psychological safety for both clients and staff. Individuals with lived experience of trauma should have a key role in identifying areas of strength and opportunities for improvement to make the physical and psychological experience more trauma informed. When reflecting upon the physical environment, organizations should ensure that the neighbourhood where services are offered is safe for collaborating providers and families.

A physically safe environment in a trauma informed organization may have some of the following characteristics:

- Well-lit exterior areas that do not allow for congregating outside entrances/exits, security guards available as needed, and monitoring of who is entering and exiting the building
- Low noise levels
- Signs that are warm, welcoming, and positive
- Seating arrangements that allow adequate space between individuals and clear sight lines of those entering a room
- Private areas to de-escalate stressful situations, promote calm, and attend to self-care
- Non-binary and gender-fluid spaces and activities
- A psychologically safe environment would:

- Include training for clinical and non-clinical staff in how to communicate effectively with clients and greet them in a welcoming and respectful manner.
- Ensure staff maintain healthy interpersonal boundaries and appropriately manage conflict.
- Provide staff and clients schedules and structures that are predictable and give adequate notice when there are changes.
- Respect the physical boundaries of staff and clients and provide options like leaving office doors open.
- Offer gender-responsive services, embrace traditional cultural connections, be culturally relevant, and address historical trauma.

Engagement and Involvement

Engagement of individuals with lived experiences, those in recovery, and those receiving services, and their families, is fundamental to trauma informed approach implementation within any service organization. This engagement needs to be intentional, meaningful, empowering, and ongoing as well as implemented across all organizational levels.

Organizations can use multiple strategies to ensure this engagement:

- Show empathy and ensure those receiving services and their families feel safe in the organization's physical space.
- Inquire about the individual's needs and those of their family, actively listen to their answers, and act upon those needs.
- Intentionally engage those in recovery, individuals receiving services, and their families in making decisions, encouraging them to speak up, and empowering them to make choices.
- Collaborate with and listen to individuals and families while developing service delivery plans and giving them options.
- Invite and encourage peer support or develop a peer support program; peers can offer support in the form of understanding and encouragement toward growth and resilience.

Screening, Assessment and Treatment Services

A trauma informed approach involves implementing screening and assessment to support consumers and identifying their needs to tailor services accordingly. Screening and assessment that adhere to trauma informed approach principles involve:

- Developing a trusting and collaborative relationship with individuals who have experienced trauma and are seeking services.

- Preventing under-recognition of trauma that can lead to neglect or re-traumatization.
- Providing an opportunity for information gathering.

Trauma screening should be universal and involve a brief inquiry to assess history of trauma, reactions to trauma, and specific behavioural health needs. Screening should be clear, straightforward, culturally appropriate, and culturally sensitive. It is essential to remember that trauma often is incorrectly viewed as a weakness and individuals who have experienced trauma may deny it.

Trauma assessment involves an in-depth exploration of the nature, severity, and timing of traumatic events and their associated effects and trauma-related symptoms. Assessment provides an opportunity for a more holistic and extensive examination and should be rooted in trust and safety. An extensively trained individual or clinician must conduct the clinical review, since it can involve psychological assessments, medical records, and interviews, and contribute to a formal diagnosis and/or pathway to care.

Treatment services must be trauma-specific, culturally appropriate, grounded in evidence, accessible, effective, and adhere to trauma informed approach principles. When a comprehensive assessment suggests that formal treatment of trauma may be warranted as part of an individual's care plan, a clinician may wish to use one or more therapeutic approaches specifically designed to address the trauma symptoms.

Progress Monitoring and Quality Assurance

Implementing a trauma informed approach is an ongoing change process that involves a shift in knowledge, perspectives, attitudes, and skills throughout an organization. Achieving this type of systems change requires continuous quality improvement. The following strategies can help organizations put structures in place to track progress:

- Prior to starting implementation, identify action steps and corresponding performance indicators for each goal.
- Results from the organizational assessment can guide an organization in identifying these goals and potential measures.
- Create a specific workgroup tasked with monitoring progress and continuously reassessing goals.
- Consider a variety of indicators to track progress and monitor impact, such as staff and client satisfaction, staff engagement, and health outcome metrics. Remember that some parameters of progress, such as increased sense of client wellness or building of stronger

rapport with the client, are important but may not be easy to measure and monitor.

- When selecting metrics, leverage existing quality improvement efforts, many of which require organizations to collect specific metrics.
- Collect and incorporate ongoing feedback from multiple sources to monitor the “temperature” of the organization during implementation.

Policy

Written policies and procedures help sustain a trauma informed approach, especially when an organization incorporates it into its mission, operating policies, and bylaws. Putting in place formal policies and procedures that reflect trauma informed principles ensures these approaches will continue, even with changes in leadership and staff.

To ensure policies support a trauma informed approach:

- Review and modify agency policies and procedures to ensure a focus on trauma (providing guidelines to support the delivery of trauma informed services and a commitment to reducing re-traumatization), safety, and confidentiality.
- Embed trauma informed principles into the organization’s mission statement, bylaws, and operating policies and procedures. Consider sharing the written policies and procedures among partner organizations. By sharing policies that have been successfully implemented, greater alignment between organizations is possible, while reducing the stress associated with its initial development.
- Within policies and procedures, clearly define the roles of individuals with lived experience of trauma in leadership/decision-making positions.
- Clearly communicate with collaborators regarding the organization’s emphasis on using a trauma informed approach.
- Ensure organizational policies attend to the emotional impacts that working with individuals experiencing trauma has on staff. This intervention can be through offered assistance, such as peer support and mutual self-help, mental health days, and an employee assistance program.
- Recognize that everyone’s experiences are unique and require an individualized approach. Formalize a process for clients, family members, and staff to feel empowered to choose how to address their trauma needs. This empowerment includes offering gender-responsive services, recognizing and addressing historical trauma, and implementing traditional cultural ways of healing.

3. Evaluation phase

Evaluation is a key component of successful trauma informed approach implementation and often takes place at multiple points in time. Before implementing a trauma informed approach, an organization should conduct a baseline evaluation to determine implementation priorities or readiness for a trauma informed initiative.

During implementation, ongoing evaluation can help determine whether the program is having an impact and how it is affecting the quality of services. The evaluation includes collecting feedback from providers, leadership, and staff, as well as those receiving services. In the long term, an organization should evaluate whether change efforts are sustained and if further refinements are needed.

There are several validated tools available to evaluate an organization’s progress in becoming trauma informed. Consider examining the following target outcomes when developing an evaluation:

- To what extent is the organization or system trauma informed?
- Does being trauma informed improve the quality of the organization’s services?
- Does the quality of the services improve clients’ abilities to meet their service goals?
- To what extent has the larger community engaged in collaborative trauma informed approach implementation?

Paediatric Psychosocial Preventative Health Model (PPPHM)

In 2007 the Paediatric Psychosocial Preventative Health Model (PPPHM) was developed by the Centre for Pediatric¹³ Traumatic Stress at the Children's Hospital of Philadelphia to provide a model to guide screening and services for all whānau of tamariki entering the paediatric healthcare system. The model acknowledges the research which shows, despite the pervasiveness of trauma, that most whānau "are competent and able to cope and adjust well over time despite initial and/or recurrent periods of extreme distress."¹⁴ In the model, higher levels of specialist care are directed to those whānau most at risk.¹⁵ Whānau may move between risk levels in the model, depending upon changes in the tamariki's medical condition. American research indicates that on average 60% of whānau entering the system will sit in the Universal segment of the model, 33% will sit in the Targeted segment and 7% will require specialist support services.¹⁶

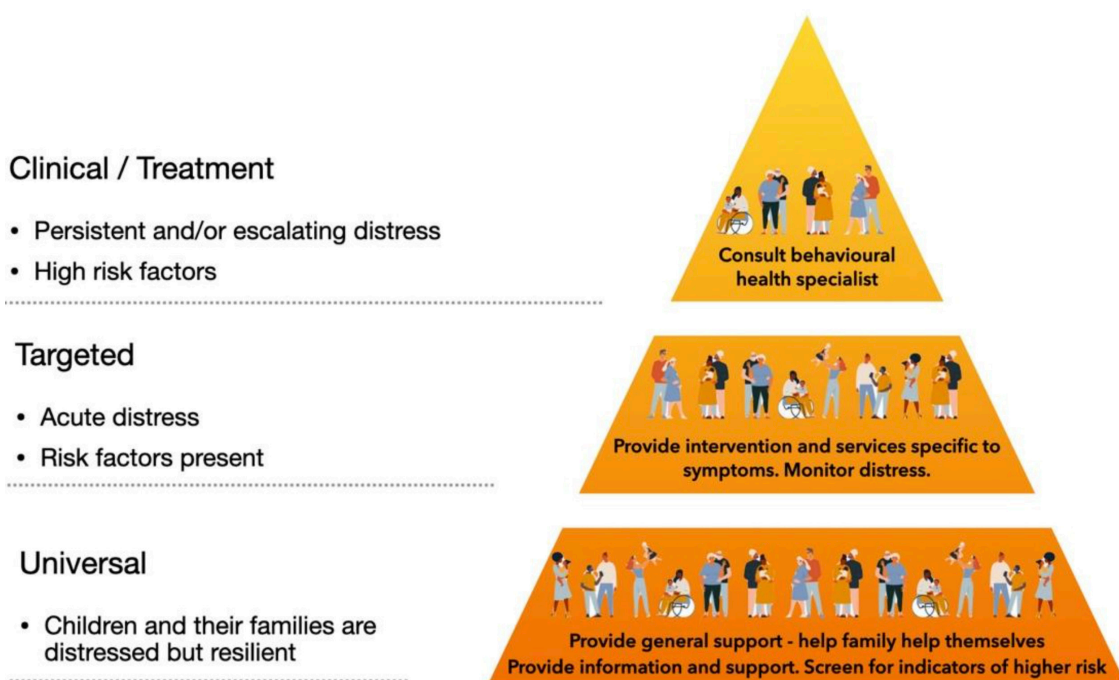


Figure 3: Centre for Pediatric Traumatic Stress, PPPHM Model, 2005.

¹³ American spelling and part of the organisation's name, so reluctantly left uncorrected.

¹⁴ Kazak, A. E., et.al., 'An Integrative Model of Pediatric Medical Traumatic Stress, *Journal of Pediatric Psychology*, 2006, 31(4) p. 1100.

¹⁵ *Ibid*, p. 1100.

¹⁶ *Ibid*, p. 1103.

Paediatric Medical Traumatic Stress Model (PMTS)

The PMTS model was also developed by the Centre for Paediatric Traumatic Stress at the Children's Hospital of Philadelphia under the directorship of Anne Kazak. The PMTS model uses a modelled traumatic experience over an illness trajectory expressed in three stages. The three stages are (1) peri-trauma, (2) treatment and, (3) long-term sequelae. Noting that each individual experiences trauma differently, across the course of this model there are multiple potential traumatic events (PTE) that are likely to cause distress and/or trauma.

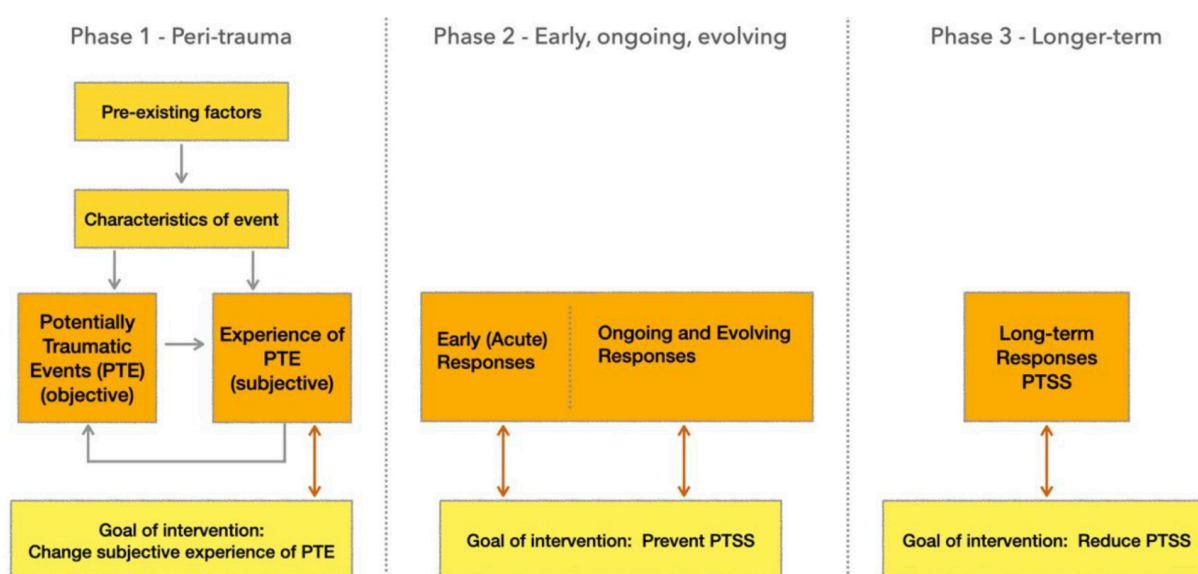


Figure 4: Paediatric Medical Traumatic Stress (PMTS) Model, Kazak, 2007.

The peri-trauma phase PTE's include diagnosis, invasive medical tests and waiting for test results. In this phase the intention of TIA is to modify the subjective experience of any PTE.

The treatment phase is variable in length and content, depending upon the child's diagnosis. Throughout this stage tamariki and their whānau are exposed to multiple PTE's including side effects of medicine, treatment complications, pain, death of other children and relapse anxiety. TIA goals shift in the second phase to preventing PTSS.

The long-term phase includes whānau of tamariki who have finished treatment, and the bereaved whānau of those who have died. In the long term the TIA goal is to reduce the effects of any PTSS that present.

Multiple studies support conceptualising a paediatric cancer treatment journey as a likely series of PTE's. Evidence includes one study where 50% of mothers and 40% of fathers met the criteria for ASD in the two weeks following diagnosis.¹⁷ In another study the parents of 126 children in treatment reported PTSS and were in the moderate to high risk range for PTSD.¹⁸

In a study of 150 adolescent survivors of childhood cancer, 99% of whānau had at least one parent re-experiencing PTSD and 20% of whānau had at least one parent with current PTSD.¹⁹ Moderate to severe PTSS has been reported in 32% of siblings of survivors.²⁰ For the tamariki with cancer themselves, 5 to 10% have PTSD²¹ with many more of them experiencing PTSS.²²

¹⁷ Patiño-Fernandez A. M., Acute stress in parents of children newly diagnosed with cancer, *Pediatric Blood Cancer*, 2008, p. 291.

¹⁸ Kazak A. E., et.al., 'Posttraumatic stress symptoms during treatment in parents of children with cancer', *Journal of Clinical Oncology*, 2005, p. 7409.

¹⁹ Kazak, A., et.al., 'Posttraumatic Stress Disorder (PTSD) and Posttraumatic Stress Symptoms (PTSS) in Families of Adolescent Childhood Cancer Survivors', *Journal of Pediatric Psychology*, 2004, p. 217

²⁰ Alderfer M. A., p. 283.

²¹ Op. cit., Kazak A., 2004, p. 218.

²² Brown, R.T., et.al., 'Posttraumatic stress symptoms in adolescent survivors of childhood cancer and their mothers', *Journal of Traumatic Stress*, 2003, p. 316.

PMTS + PPPHM – The Blueprint

In 2007 the Kazak team blended the PMTS and PPPHM models to create the blueprint. They consider that this model guides the development of risk-based interventions, to all whānau throughout the cancer journey, from diagnosis through to survivorship.²³

Understanding that each whānau's situation is different, the strength of this model is that it covers all whānau with the key variable being the type and intensity of intervention.

As this is a clinical model, the first step is an assessment of the whānau's level of psychosocial risk. The team uses a tool devised by Kazak in 2003. The Psychosocial Assessment Tool (PAT) is able to categorise whānau into the PPPHM risk categories.²⁴ Despite this being a clinical model, the research identifies that within the Universal category, there is the opportunity to "partner with community cancer-based organisations that may reach survivors and their family members, offering the opportunity to provide anticipatory guidance and assessment."²⁵

Bereaved whānau

Note that Universal "I" category (PPHM Universal + PMTS Phase 3) also applies to bereaved whānau. The research in this area is limited, however Kazak identifies that more needs to be understood regarding the whānau's needs immediately before the child's death, at the time of death and in the weeks, months and years afterwards. The authors also recognise the need for "increased (and earlier) involvement of formal paediatric palliative care, with a focus on better management of a dying child's physical and emotional symptoms ... to minimise the potential for trauma by maximising the child's comfort and providing families with the experience of a 'good' death."²⁶

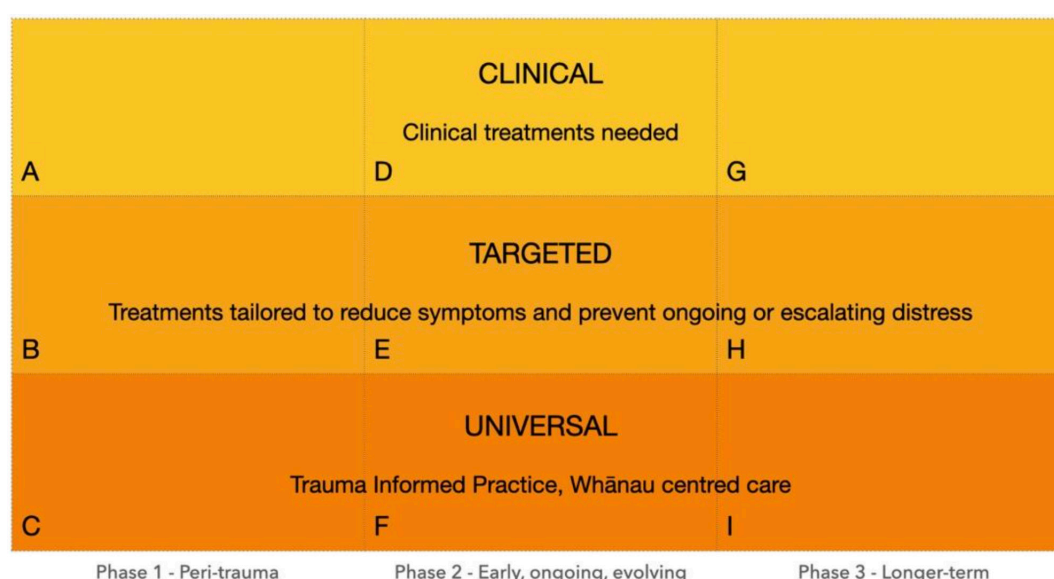


Figure 5: PPPHM combined with PMTS provides a blueprint for psychosocial care 2007.

²³ Op. cit. Kazak, A., 2006, p. 1102

²⁴ Op. cit. Kazak, A., 2006, p. 1102.

²⁵ Op. cit. Kazak, A., 2006, p. 1104.

²⁶ Op. cit., Kazak A., 2007, p. 1104.

National Child Traumatic Stress Network (NCTSN) DEF Model

In nursing practice in most English-speaking jurisdictions, the ABC protocol is a method for prioritising patient care and treating patients with critical injuries or severe illness. ABC is an acronym that stands for Airway, Breathing and Circulation.²⁷ The model is a shorthand way of remembering 3 critical areas of treatment in emergencies:

Airway: When the airway is compromised it can be life-threatening.

Breathing: Oxygen is a critical requirement for the oxygenation of organs and tissues.

Circulation: Blood flow delivers oxygen and nutrients to cells around the body while also removing waste products. Disruption to circulation can lead to organ failure and even death.

The NCTSN proposed the 'DEF' Model as a similar treatment tool to the nursing ABC's. This model is an aid to remember three critical mental health and wellbeing "trauma informed" dimensions, which includes assessing whānau. This model is increasingly used in hospital settings. It provides a straightforward and reliable method for identifying, preventing and treating traumatic stress when it is needed.

The DEF dimensions are:

Distress: Assess and manage pain. Ask about fears and worries. Consider grief and loss. Act to reduce distress.

Emotional support: Who and what does the patient need now? What barriers are there to mobilising support services? Act to promote emotional support.

Family: Assess parents, siblings and others who are in distress. Gauge family stressors and resources. Address other needs, beyond physical medical needs. Act to remember and include the family.

D-E-F PROTOCOL for Assessing and Treating Children and Families with Traumatic Stress	
D	DISTRESS for brief assessment and recommended interventions to address and treat pain, fears and worries, and grief and loss. Recommendations include: <ul style="list-style-type: none"> • Actively assess and treat pain, using your hospital's protocol • Provide child with information about what is happening and choices regarding treatment decisions when possible • Listen carefully for child's understanding and clarify any misconceptions • Ask about fears and worries • Provide reassurance and realistic hope
E	EMOTIONAL SUPPORT for brief assessment and recommended interventions to address child's emotional needs, and barriers to mobilising existing supports. Recommendations include: <ul style="list-style-type: none"> • Encourage parents to be with their child as much as possible and to talk with their child about worries and fears. • Empower parents to comfort and help their child • Encourage child's involvement in age-appropriate activities when possible
F	FAMILY for brief assessment and recommended interventions to address parents' and siblings' distress, family stressors and resources, and needs beyond medical care. Recommendations include: <ul style="list-style-type: none"> • Gauge family distress and other life stressors; identify family strengths and coping resources • Encourage parents to use own coping resources or support available at the hospital or in the community
D E F	QUICK SCREEN to identify and assist those who have traumatic stress symptoms or who are at greater risk for traumatic stress. Recommendations include: <ul style="list-style-type: none"> • Involve psychological staff in a team-based approach for those at higher risk • Make referrals to hospital or community-based mental health resources when appropriate

Figure 8: NCTSN, Pediatric Medical Traumatic Stress: A Comprehensive Guide, 2014.

²⁷ Mielke R.K., 'Mastering the Basics: The ABC's of Nursing', Nurse.com, Retrieved 18 December 2024

The graphics below show a card from the NCTSN that is designed for staff to carry in their pocket.

Traumatic Stress in Ill or Injured Children		
AFTER THE ABC'S CONSIDER THE DEF'S		
D	Distress	<ul style="list-style-type: none"> • Assess and manage pain. • Ask about fears and worries. • Consider grief and loss.
E	Emotional Support	<ul style="list-style-type: none"> • Who and what does the patient need now? • Barriers to mobilizing existing supports?
F	Family	<ul style="list-style-type: none"> • Assess parents' or siblings' and others' distress. • Gauge family stressors and resources. • Address other needs (beyond medical.)

QUICK SCREEN	
Is this child at risk for ongoing traumatic stress reactions?	
<p>ASK PARENT: Since this has happened, does your child...</p> <ul style="list-style-type: none"> • get Physical symptoms if reminded of the illness or injury? • try not to Talk about it? • Startle easily (for example, jump at sudden noises?) • get very Distressed if reminded of the illness or injury? <p>ASK CHILD:</p> <ul style="list-style-type: none"> • Have you been really scared or thought you might die? • Does a sudden noise really make you jump? • Do you feel very upset when something reminds you of being sick or hurt? • Do you have people who care about you and pay attention to what you say? <p>REMEMBER RISK FACTORS:</p> <ul style="list-style-type: none"> • Severe pain at any time? • Exposed to scary sights and sounds? • Separated from parents or caretakers? • Loved ones ill or injured? Did anyone die? • Other losses such as, home, pet, belongings? • Is child mourning loss of ability, body image, or future? • Prior scary experiences? • Prior behavior problems? <p>If multiple concerns or risk factors present, arrange follow-up and consider referral for further assessment.</p>	

DEF Model Case Study from NCTSN

Reprinted from the NCTSN Pediatric Medical Traumatic Stress Toolkit for Health Care Providers:

2 WEEKS

3 WEEKS

1 MONTH

Maria is a typical 13 year-old girl — active, social, and friendly. One day, she complains to her mother of “not feeling quite right.” A few days later, Maria looks pale and complains of being tired all the time. She begins missing school and after school activities...

Maria’s mother becomes concerned and takes Maria to her pediatrician, thinking that she might have the flu or be anemic. The doctor examines Maria and does some blood tests. The next day, the doctor recommends that Maria and her mother see a specialist at the hospital for further evaluation for cancer.

More tests are done. Maria’s father leaves work early to join them at the hospital. The doctor tells mom and dad that they think Maria may have cancer, but he wants to admit her and do more tests to be sure. Mom and Dad become very worried. They arrange for their 15 year-old son, Anthony, to stay overnight with his grandmother.

Maria feels sick, but also feels scared and worried when she realizes that she may have cancer. She tells her mom that she wants to go home. Mom agrees to stay with Maria at the hospital and reassures her that the doctors have a lot of experience in treating patients with all kinds of illnesses.

Two days later, a team of oncologists tells Maria’s mom and dad that Maria has Leukemia — a common form of cancer in children. They give them comprehensive information regarding diagnosis and treatment, which includes chemotherapy. The doctors seem very hopeful. Maria’s parents can’t believe that Maria has cancer, and feel empty and numb at the news. Mom keeps thinking: “but she was fine two weeks ago...”

Maria’s parents and medical team tell Maria that she has cancer, and that it can often be treated with good success. However, she will need to stay in the hospital for awhile for treatment. Maria’s mother promises to stay with her. Maria gets upset and cries — she wonders to herself whether she will die. Maria’s parents try to be reassuring, even though they are unsure of how they feel themselves.

Maria begins meeting a lot of people — doctors, nurses, a social worker, and a teacher who will help her keep up with her schoolwork. The nurse also tells her about other teens on the floor with cancer. Even though she thinks that everyone is nice, Maria doesn’t want to say much to them. She gets upset when her mom leaves the room for just a few minutes.



Intervention Point #1: ADMISSION

D E Providers and staff admitting Maria should understand that:

1. Unexpected hospitalization is associated with increased risk for posttraumatic stress for children and parents.
2. Like other families in their situation, Maria and her parents feel very anxious due to unexpected admission and uncertain diagnosis/prognosis.

Intervention Point #2: DIAGNOSIS & TREATMENT PLANNING

D E F Providers treating Maria should be aware that:

1. Time of diagnosis can be especially traumatic for children and families, and can be impacted by their perception of life-threat.
2. Perception of life threat can be unrelated to (objective) prognosis. Parents who believe that their child might die or children who believe that they will die can be at increased risk for posttraumatic stress.
3. As is the case with Maria and her parents, most initial responses to diagnosis, including shock and disbelief; crying; feeling worried or overwhelmed are common and often temporary.
4. Recent losses within the family or other family stressors can increase risk of posttraumatic stress responses.

See page 7 for recommended assessments and interventions for Maria and her family.

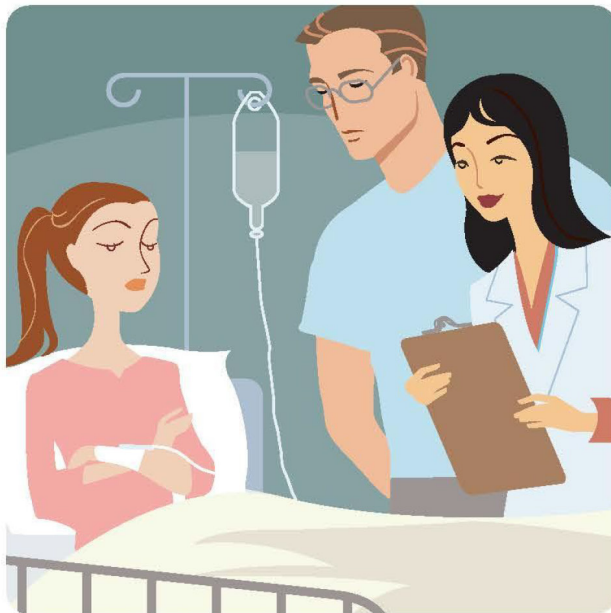
3

1 1/2 MONTHS

Maria's father brings in a package with cards and letters from Maria's friends and teachers at school. Maria is happy to hear from her friends. Her mother and the social worker help her decorate her room with the cards. Maria's mom suggests that she write a thank you letter to the school. The social worker recommends that Maria keep a journal of her hospital experience, as other teens have found this helpful. The social worker also suggests that she may be able to share parts of her journal with her friends and teachers after she returns to school.

Finally, with some encouragement, Maria begins to leave her room on a regular basis. She likes going to the group room for school lessons and the recreation room with the computers, books, and games. She begins meeting other patients with cancer, including some who have no hair and who look sick. Maria thinks she has little in common with them, and at first, doesn't want to make friends with them.

Maria's treatment is painful at times. Some of the medicines make her sick; she doesn't want to eat, and at times, she throws up. While she writes in her journal periodically, most days she says she "doesn't have anything to say." Her dad comes every night, and her brother frequently visits on weekends, along with her aunt. One night, Maria asks her mom: "Am I going to die?" Mom reassures Maria that both they and her doctors believe her cancer is treatable, and because of the chemo, she is going to feel sick sometimes. But privately, Mom is upset at seeing her daughter so ill, and wonders about whether she will die.



2 1/2 MONTHS

4

Intervention Point #3:

ADJUSTING TO INPATIENT TREATMENT

E Providers treating Maria while inpatient should be aware that:

1. Like Maria, children can initially feel isolated, alone, and self-conscious during a hospital stay. As a result they may withdraw from family and friends or feel depressed. These initial responses are often temporary, and improve with support.
2. During an initial hospital stay, children and parents often don't know what to expect. What may seem "routine" to providers, staff, and experienced families can seem unfamiliar, awkward, and sometimes frightening to newly admitted children and families. It is helpful to spend extra time with children and families initially, and to explain routines and procedures to them in advance.

Intervention Point # 4:

D E F COPING WITH PAINFUL TREATMENT

Providers treating Maria should be aware that:

1. Children who experience significant pain or painful treatment can experience traumatic stress reactions during treatment and are at increased risk for persistent posttraumatic stress.
2. In dealing with painful treatment, children and families sometimes feel helpless. It is often difficult for parents to see their children in pain. Combining the use of pharmacologic and behavioral interventions (e.g., teaching relaxation or distraction techniques) for pain management is often helpful.

See page 7 for recommended assessments and interventions for Maria and her family.

3 MONTHS



Maria's doctors decide she can go home for two weeks during a down cycle. At first, Maria feels very excited and happy to be home. Then, as the family tries to readjust to normal routines and expectations, Maria feels irritable because things don't feel the same to her. She and Tony fight a lot. After a week, Maria begins to feel very tired. She doesn't want to eat. She begins to have a fever one evening.

Maria's mother calls the doctor. They tell her to take Maria to the emergency department and she is readmitted. Maria begins to cry — she wants to go back home. The nurses stop by to say “Hi” and to tell her that they've missed her — but she doesn't want to talk to them. Mom suggests that they re-decorate Maria's new room, but she doesn't want to. Maria feels very angry to be back so soon.

Maria's treatment resumes. After a few days, clumps of Maria's hair begin to fall out. The social worker talks with Maria and her mother about how other patients have coped with having their hair fall out. Maria doesn't like the idea of wearing a wig, and she doesn't want a lot of other people to see her. She cries a lot and seems to withdraw from the staff and other patients at the hospital.

5 MONTHS

Slowly, with support from her family and treatment team, Maria begins to cope with the changes in her appearance. Thanks to her friends, she has a new collection of cool hats to wear. Still, she has good days and bad days. She begins to interact with other teens and staff on the floor again. She develops a pen-pal relationship with an older girl who had the same type of cancer a few years earlier and is now finished with treatment.

A few weeks later, Maria gets excited when the doctors say that she will soon be ready for treatment at the outpatient clinic. But, she worries about going home too; she's not sure how her friends will react, or if they will understand what she's been through. Mom is worried about how she will cope with all of Maria's medical needs at home, without the medical team around. She thinks to herself — “What if something happens to Maria and I'm not able to help her in time?”

Intervention Point #5: TREATMENT SETBACKS & EMOTIONAL REACTIONS

D E Providers treating Maria should be aware that:

1. Like Maria, common emotional responses to treatment and setbacks can include feeling sad, depressed, irritable, angry, scared, or withdrawing from others. These responses are often transient and improve with patience, understanding, and support.
2. Some children and parents experience treatment setbacks as failures, rather than as a “bump” in the treatment road. Setbacks can also trigger earlier distress and emotional reactions.
3. Emotional support and family resources are vital to helping children and families deal with emotional effects and treatment setbacks.

Intervention Point #6: DISCHARGE PLANNING

E F Providers treating Maria should be aware that:

1. Some families experience discharge as a time when they lose medical support and a sense of safety. They can worry about coping with medical and treatment issues at home, without frequent support. Providers can help families anticipate challenges they will face and problem-solve with them in advance, as well as provide reassurance.

See page 7 for recommended assessments and interventions for Maria and her family.

Maria finally goes home. The re-adjustment is difficult at first. Mom is anxious about letting Maria do the things she did before, while dad thinks the family should be getting back to normal. Maria's brother, Tony, is mad that Maria is getting "special treatment" at home, too. Maria has brief visits with friends, but she still feels different from them. Once a week, she gets a knot in her stomach when she has to go back to the outpatient clinic for treatment. There is talk of going back to school, but Maria is not sure if she's ready to go back. She worries that other kids at school might make fun of her or say things about her.

Maria *begins to adjust to outpatient treatment and life at home. Mom is less anxious about letting Maria do things on her own and has been giving her small chores to do around the house. Dad seems more relaxed, too. Tony, is more sympathetic and recently asked Maria a lot of questions about being in the hospital and having cancer. Maria's friends are visiting more often and she was able to attend an art show at her school where one of her drawings was displayed. Her parents and doctor have begun making plans for Maria to go back to school part-time. She is writing in her journal again.*



6 MONTHS

6

Intervention Point # 7:

OUTPATIENT TREATMENT

E F Outpatient providers treating Maria should be aware that:

1. Having a life-threatening illness can be traumatic for children and families, and can be impacted by perception of life-threat. Parents who believe that their child might die or children who believe that they could die can be at increased risk for persistent posttraumatic stress.
2. As in Maria's case, the transition from hospital to home can be difficult. Families can feel isolated from social and medical supports. Parents, children, and siblings may become irritable and anxious while trying to reestablish normal routines and expectations. Children may look and feel different and worry about how friends will react. These reactions are common, but can improve with understanding, support, and advance planning.
3. Recent losses within family or other family stressors can increase risk of posttraumatic stress during and after treatment.
4. Parents and siblings can also be affected, even after treatment ends. Some parents become hypervigilant for signs and symptoms that the illness has returned. Siblings may worry in private about their brother or sister. They may also feel jealous of the special attention their sibling is getting.

See page 7 for recommended assessments and interventions for Maria and her family.

How can I help Maria (and others like her) within the scope of my job?

ADMISSION:

- Provide simple explanations about what is happening and realistic expectations about what will happen next to reduce fears and worries.

DIAGNOSIS AND TREATMENT PLANNING:

- Acknowledge common emotional reactions to trauma and traumatic stress.
- Ask about fears and worries.
- Connect parents to family support resources in the hospital.
- Provide simple explanations about medical procedures and treatment to the child and family to reduce fears and worries.
- Provide child with as much age-appropriate involvement as possible in treatment planning.

ADJUSTING TO INPATIENT TREATMENT:

- Connect children and parents to supportive resources in the hospital.
- Provide simple explanations for medical routines and procedures to the child and family to reduce fears and worries.
- Help families establish daily routines and behavioral expectations, when possible.
- Identify family strengths and resources. Gauge family distress and other stressors.

COPING WITH PAINFUL TREATMENT, EMOTIONAL EFFECTS, AND TREATMENT SETBACKS:

- Acknowledge common emotional reactions to pain, painful treatment, and setbacks.
- Encourage and promote a stepped approach to confront emotionally painful thoughts, fears, worries and avoidant reactions.
- Combine pharmacologic and behavioral interventions (e.g., relaxation and distraction techniques) for pain management.
- Involve psychosocial staff in a team-based approach to helping the child and family experiencing setbacks or difficulties in treatment.

DISCHARGE PLANNING:

- Anticipate challenges in returning to the home environment and help families plan accordingly.
- Support child's physical and emotional transition to the home environment.

OUTPATIENT TREATMENT:

- Monitor child and family's physical and emotional recovery.
- Connect parents to family support resources in the community.
- Make referrals to mental health resources for children and families with symptoms of traumatic stress and those who are at increased risk. (See QUICK SCREEN.)

D-E-F Protocol for Assessing and Treating Children and Families with Traumatic Stress

D DISTRESS - Use brief assessment and indicated interventions for distress (see pocket card,) including:

- Provide child with as much information about what is happening and choices in decisions as possible.
- Listen carefully for child's understanding and clarify any misconceptions.
- Ask about fears and worries.
- Provide reassurance and realistic hope.

E EMOTIONAL SUPPORT - Use brief assessment and indicated interventions for emotional support (see pocket card,) including:

- Encourage parents to be with their child as much as possible and to talk with their child about worries and fears.
- Empower parents to comfort and help their child.
- Encourage child involvement in age-appropriate activities when possible.

F FAMILY - Use brief assessment and indicated interventions for family needs (see pocket card,) including:

- Gauge family distress, coping resources, and other stressors.
- Encourage parents to use own coping resources or resources available at the hospital or in the community.

D E F Use QUICK SCREEN (see pocket card,) to identify those who have traumatic stress symptoms or who are at greater risk for traumatic stress.

- Involve psychosocial staff in a team-based approach for those at higher risk.
- Make referrals to mental health resources when appropriate.

Te Pou Implementation Framework

Te Pou is New Zealand's national centre of evidence informed workforce development for mental health, addiction and disability sectors. It has been researching the use of trauma informed approaches and trauma informed care since 2018, when it started exploring how best to implement a trauma informed approach in delivering mental health and addiction services. The NZ Ministry of Health's Oranga Hinengaro – Service and System Framework 2023, subsequently identified trauma informed and healing/restorative centred care as one of five guiding service principles, further embedding trauma informed approaches as critical to quality holistic healthcare services.

System Principles	Service Principles
Shaping decisions about the health system's oranga hinengaro responses: <ul style="list-style-type: none"> • Person and whānau centred • Human rights • Holistic • Equity-driven • Accessible • Community-focussed • Social inclusion and anti-discriminatory • Collaboration and innovation 	The foundation for decisions and approaches when delivering services for oranga hinengaro needs: <ul style="list-style-type: none"> • Self-determined recovery • Harm reduction • Preventing suicide and targeted supports • Trauma informed and healing/restorative centred care • Strengths-based

Figure 9: Ngā Mātāpono Principles, Oranga Hinengaro, 2023.

In more recent times Te Pou published a framework, informed by ongoing evidence based research, describing the values and skills sets required to deliver on their vision of trauma informed care. This framework now informs the "Let's get real"²⁸ skills development programme.

The framework proposes Seven Steps:²⁹

1. Pre-implementation work
2. Collaborative discussions
3. A shared vision and rationale for a trauma informed approach
4. An implementation plan
5. Incorporation into organisation policies and procedures
6. Ongoing training and upskilling for the whole workforce
7. Shared evaluation, review, feedback and adjustments

²⁸ "Let's get real" skills development programme can be found here: <https://www.tepou.co.nz/initiatives/lets-get-real>

²⁹ Te Pou, "Trauma Informed Approach: An update of the literature", Te Pou, 2024, p. 19.

The Seven Step Process

Implementation step	Activities in this step include:
Pre-implementation work	Identify change leaders/champions, change methods, evaluate readiness and capacity for change. Create a supportive culture for change, including employee self-care, training and mentoring. Identify important systems, policies and processes. Consider evaluation (including barriers to change) and monitoring methods. Understand how stakeholder partnership and engagement will work, particularly how collaboration with Māori will work and how tino rangatiratanga will be upheld.
Collaborative discussions	Collaborative discussions with stakeholder groups to ensure co-design of process and outcomes. Stakeholders should include persons with lived experience as well as tāngata whaiora and whānau. Noting that a trauma informed approach may not succeed if it is designed for a singular setting.
A shared vision and rationale for a trauma informed approach	As concepts and contexts for trauma informed approach can vary in practice, a shared vision of what is best for the organisation's stakeholders and specific place is important. Investing in this step avoids misunderstandings between participants based on different assumptions.
An implementation plan	An implementation plan is a helpful expression of intention and a guide or roadmap that describes stages of a process through which the change will occur. Choice of change model would inform the development of this implementation plan. Other tasks in this step include identifying the scope of change and the teams that would be required to change, choosing a programme sponsor, pilot activities, timeframes, change champions and communication channels.
Incorporation into organisation policies and procedures	Integrate trauma informed approach into the policies and procedures of the organisation to increase the likelihood that trauma informed approach will be successfully implemented and maintained over time. Other tasks in this step would include how feedback and lessons learned would occur, amendment and/or development of policies, workforce self-care, peer support and lived experience involvement. An important note is the requirement for policies and procedures to be flexible in service and to enable the principles of empowerment and choice.
Ongoing training and upskilling for the whole workforce	A change that is able to be sustained requires a workforce that is well supported to continue the trauma informed practice. Ensuring practices and methods are grounded in kaupapa Māori values is critical to recognising the ongoing impacts of colonisation and intergenerational trauma this is likely to require a programme of stakeholder development and learning. Some types of induction and/or training may be compulsory activities. Regular follow-up and refresher learning or case study examples are all helpful learning reinforcement activities. For specific employees, reflective supervision methods may be required. Stakeholder wellbeing and celebrating progress are important considerations in the development of the workforce.
Shared evaluation, review, feedback and adjustments	Ensuring plans include co-designed measures and data collection mechanisms to regularly review progress supports accountability. Some involve healthcare providers' knowledge and attitudes pre and post training, others also involve stakeholder feedback. Adjusting the approach based on review data supports successful implementation and when done openly boosts stakeholder confidence in the change process.

Barriers to Implementation

Te Pou's "Trauma Informed Approach"³⁰ also identifies barriers to successful implementation. They are:

- Individual role expectations
- Inconsistencies between policy and workforce understanding
- Inadequate time for change
- Unclear benefits
- Stakeholder resistance or lack of confidence
- Uncertainty of how to respond or refer
- Not adequately engaging with Māori
- Systemic barriers in NZ health organisations
- Change is not an organisational priority
- Lack of leadership commitment
- Power differentials/discrimination between lived experience, employees and clinicians
- Funding shortfalls
- Inadequate training
- Lack of evaluation and course correction
- Poor team collaboration
- Legislative or statutory environment
- COVID impact on workforce

Promoting Resilience in Stress Management for Parents (PRISM-P) Resilience Model

The PRISM-P model has been included in this volume as a result of research described in Volume One. This model provides more detail of a paper that investigated the extent to which individual resilience might be improved by supporting the development of coping skills in parents. A meta-analysis by Luo³¹ that reviewed two randomised clinical studies³² of 71 parents identified beneficial improvements in the personal resilience of parents using the PRISM-P intervention model.

The Promoting Resilience in Stress Management for Parents Model

The PRISM-P Model has been adapted from the PRISM Model, which was developed for adolescents and young adults with serious illnesses by the Seattle Children's Hospital. The goal of the model is to "build practical skills that will bolster individual resilience resources in the face of stress."³³ The PRISM-P is a manualised intervention that can be administered by a trained non-clinical professional. PRISM-P 'Interventionists' received 8 to 10 hours of supervised training, including role playing and practice scenarios.

Parent distress levels were assessed with the Kessler-6 Psychological Distress scale, which has been extensively validated and is used globally. Parent resilience levels were measured using the 10-item Connor-Davidson Resilience Scale (CD-RISC), which has been widely used and similarly validated in the research literature. Intervention sessions were carried out face to face while follow up sessions were carried out through digital platforms.

Studies report a high degree of parent attrition as a result of time pressures and refusal to complete due to 'personal issues' or spending time away from their sick child. This may lead to earlier interventions being less successful.

A possible limitation of the model is that it focuses on "bolstering individual caregiver resources, with the hypothesis that they would extend to the overall health of the child and then the larger family unit."³⁴ This approach may not be culturally appropriate in an Aotearoa New Zealand context because it focuses on the individual rather on the whole whānau.

³⁰ Te Pou, 'Trauma Informed Approach: An update of the literature' 2024, p.16.

³¹ Luo, Yh., Xia, W., He, Xi. et al. *Psychological interventions for enhancing resilience in parents of children with cancer: a systematic review and meta-analysis.* *Support Care Cancer*, 2021.

³² Rosenberg A.R. (2019) and Yi-Frazier J.P. (2017).

³³ Y-Frazier J.P. et.al. p.342.

³⁴ Ibid. p.348.

Table 3: Summary PRISM-P Intervention Session Details³⁵

PRISM-P Domain	Resilience-building pillars/topics	Details
Managing stress	Stress-management/ coping	Breathing techniques, mindfulness skills including breathing and relaxation strategies, obtaining social support and acceptance of stressors.
	Goal setting	Setting specific, realistic, desirable goals, planning for their achievement, strategies for dealing with roadblocks, identifying alternative pathways and how parent/caregiver can help meet goals.
Building resilience	Cognitive restructuring	Recognising negative self-talk, identifying unrealistic/negative thoughts, replacing these thoughts with positive/manageable ones.
Follow-up	Benefit finding	Reframing current experience into a meaningful one, self-reflection/mindfulness, journaling. Reflection of intervention strategies and overall satisfaction identification and recognition of successes, and referrals for further resources needed.

The Promoting Resilience in Stress Management (PRISM) intervention

Enrolled parents are invited to complete the sessions and complete assessments throughout the process to track progress.

- Individual (1:1) sessions. Parents will schedule 4 separate sessions to be conducted approximately every 1-2 weeks
- Parents will also receive once monthly “booster” contacts until they reach the 6 month point from enrolment. Each session is 60 minutes long. The first visit is conducted in person, and follow-up sessions can be conducted either in person, by phone, or online. Ongoing Booster sessions will be brief (10-20 minute). All interventions will be administered by a trained non-clinical or clinical professional.
- Sessions will be audio-recorded for fidelity. A supervisor will review the first 5 and then 1 of 4 randomly selected sessions for each interventionist. Staff receive feedback and approach with each participant is refined if needed.
- Group-based sessions. Half-day long symposia to cover all 4 of the first PRISM sessions in one sitting are scheduled to take place either in person, online, or by phone. These workshops will be led by and/or facilitated by the Primary Investigators or by trained non-clinical or clinical professionals. Light refreshments will be available for participants throughout the session.
- Following each session, parents will be asked privately if they wish to share/connect online with others in the group. Staff provide once monthly “booster” contact via email to the whole group, checking in and inviting the group to virtually share practiced skills and experiences. Emails to the group will be monitored by study staff and participants will be reminded not to share patient-identifying information. Group in person sessions take place at Seattle Children’s Hospital, so participants travelling more than 20 miles round trip may be compensated for their mileage driven (~ \$0.54 per mile).
- Standard Psychosocial Care. The Standard of psychosocial Care (SOC) at Seattle Children’s includes an assigned social worker for each family. These professionals provide a breadth of services including administrative assistance with concrete needs (e.g., housing, insurance, financial aid, work leave), as well as directed clinical support based on comprehensive needs assessments conducted at the time of diagnosis. Ongoing support includes approximately weekly check-ins with families and additional referrals, as needed, for directed psychological or other support.

³⁵ Seattle Children’s Hospital, PRISM Study Protocol v. 06.14.2017, p.8.

Conclusion

- Published peer-reviewed research at the time of publication focuses primarily on the application of a trauma informed approach and trauma informed care in clinical settings. Few papers discuss or even refer to non-clinical paediatric oncology support services. More useful information on the application of a trauma informed approach is available in the grey literature through organisations like the Te Pou, Te Kotahi Research Institute, National Child Traumatic Stress Network (US) and Phoenix Australia who provide advice and/or training on trauma informed care in non-clinical settings.
- Lessons regarding implementing a trauma informed approach are able to be gleaned from trauma informed approaches in non-oncology settings. Mental health and addiction services are in many jurisdictions the source of methods and models that have been applied in healthcare service settings. These organisations are a helpful source of information and resources and may be useful future collaborators.
- The health and wellbeing benefits of a trauma informed approach to tamariki, whānau and staff carers has been repeatedly proven in the published research.
- Barriers to successful implementation of a trauma informed approach exist but are able to be mitigated with careful planning, a timely reminder that the planning stage of any trauma informed care implementation should not be rushed.

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