

**EVIDENCE CENTRE**  
TE POKAPŪ TAUNAKITANGA

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# Respite Care

Benefits to Wellbeing

March 2021



**ORANGA  
TAMARIKI**  
Ministry for Children

# EVIDENCE CENTRE

## TE POKAPŪ TAUNAKITANGA

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The Oranga Tamariki Evidence Centre works to build the evidence base that helps us better understand wellbeing and what works to improve outcomes for New Zealand's children, young people and their whānau.

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Oranga Tamariki has made every effort to ensure the information in this report is reliable, but does not guarantee its accuracy and does not accept liability for any errors.

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# EXECUTIVE SUMMARY

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The purpose of this evidence brief is to consider how respite care contributes to wellbeing for children and for their caregivers, to inform policy and practices regarding the types and range of respite care that could be provided as part of the Oranga Tamariki aim to keep families together.

This evidence brief addresses five research questions:

- How is respite care provided in Aotearoa New Zealand and other jurisdictions, for children outside of, or within, the state care and protection system?
- What is the evidence for respite care (formal and informal) being beneficial to the wellbeing of children and young people?
- What is the evidence for respite care (formal and informal) being beneficial to the wellbeing of the parent/caregiver?
- What is the evidence for respite care (formal and informal) contributing to stability in care arrangements?
- What are the attributes of respite models of care that result in wellbeing benefits for the child and/or the parent/caregiver?

To address these questions, a literature search was carried out. In all, 50 items were included. Items published between 2015 and 2020 were sought through the literature search. Eleven items published prior to 2015 and two items that are undated were also included – either because they provided important evidence, or because they contributed to an unpublished early draft of an evidence brief, which is described further below. The jurisdictions of interest were Aotearoa New Zealand, Australia, Canada, Republic of Ireland, United Kingdom (U.K.), and United States of America (U.S.).

The 50 items include three which Oranga Tamariki specifically requested be included:

- Two Oranga Tamariki publications from 2019, each reporting the results of a survey with Oranga Tamariki caregivers; and
- An unpublished draft evidence brief, with content that overlaps with the present evidence brief.

The evidence brief provides a high-level overview of relevant evidence and offers a description of key research findings. The brief does not offer a critique or evaluation of the evidence. Given the nature of this evidence brief, it should be considered a general descriptive document to be read in conjunction with referenced sources.

## Four models of care are used within the jurisdictions of interest

Four main models of care are discussed in the literature: in-home respite care, centre-based respite care, residential-based respite care, and residential respite care camps. These different models of care result in different benefits to children and to their caregivers.

In-home respite care tends to provide very brief respite for the caregiver, usually (but not always) for hours rather than days.

Centre-based programmes are often time limited, such as providing four to six months of two to three periods of facility-based sessional care. In centre-based care, respite is often one aspect of a wrap-around programme aimed at the household. Better outcomes are commonly observed where the family or household takes greater advantage of the full wrap-around service rather than simply using the respite care component.

Residential-based care tends to focus on the needs of the child rather than providing wrap-around care for the family, with the caregiver simply benefitting via the break in routine. Residential experiences are suggested to benefit the child or young person, first and foremost, through being in an environment with peers with whom they have a shared experience.

Residential respite care camps are a subset of residential-based care, but the camp environment is an important differentiator. In the camp environment, children and young people benefit from new and challenging activities, some physical, and others that help them develop socially.

Health camps and school camps have had an important part to play in the lives of many children and young people in Aotearoa New Zealand over many generations. The literature about the benefits of participating in a holiday camp suggest this model of care offers considerable benefits to children, young people, and to their caregivers too, where the camp is designed as a family/household affair. This model of care offers a good opportunity for planned respite care that can be considerably tailored for different age groups and different needs and interests. The benefits children and young people reap from camp-based respite care appear to be cumulative.

### **There is evidence that respite care benefits children through improved socialisation, new skills and experiences, improved resilience, and enhanced self-esteem**

Most of the evidence of respite care benefits for children and young people have emerged from literature relating to respite care camps.

### **There is evidence that respite care benefits caregivers by providing a break from their normal caregiving duties**

The opportunity for a 'break' reduces stress; allows for family time; improves family functioning; improves caregiver mental health, including reducing distress and depression; and improves marital quality. The benefits to the caregiver are greatest when respite care is used regularly, normatively, and for appropriate durations.

### **Respite care has been shown to prevent placement breakdown, and reduce the likelihood of entry to full-time care**

Care stability is considerably supported by respite care, with 'edge of care' programmes having good outcomes in terms of reducing the likelihood of the child or young person entering full-time care. A common experience amongst caregivers in all jurisdictions is that there is a lack of respite care provision compared to need.

### **Attributes of respite care that result in improved wellbeing include non-judgemental service provision, attention to the individual needs of the child, quality of care, and having a consistent respite carer**

There is considerable agreement in the literature about the attributes of quality respite care, across children and young people, their caregivers, and service providers.

# BACKGROUND

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Respite care tends to be of longer duration than periodic childcare. It aims to give the caregiver<sup>1</sup> a break from their care giving duties in which to refresh, reenergise, or recharge, prior to resuming their caregiver role. As a support service, respite care may be a pathway to increased stability for children in care, reducing the frequency with which they are moved into the care of a different caregiver. At present there are concerns within Oranga Tamariki that:

- there is little guidance around the provision of respite support;
- respite is not consistently provided to caregivers; and
- there is variation in the approach to respite care across Oranga Tamariki sites.

Oranga Tamariki has emphasised that its goal is for children to remain in the care of their families. In this context, the aim of respite care is to support children and their caregivers in difficult times.

Oranga Tamariki wishes to consider the types and range of respite care that it could provide, informed by models used in other jurisdictions.

This evidence brief primarily focuses on how respite care contributes to child wellbeing. It reports what the literature says about the benefits to child wellbeing when the child and main caregiver spend some time apart, through respite care.

## The Research Questions

This evidence brief addresses five research questions, presented below in a non-hierarchical list.

- How is respite care provided in Aotearoa New Zealand and other jurisdictions, for children outside of, or within, the state care and protection system?
- What is the evidence for respite care (formal and informal) being beneficial to the wellbeing of children and young people?
- What is the evidence for respite care (formal and informal) being beneficial to the wellbeing of the parent/caregiver?
- What is the evidence for respite care (formal and informal) contributing to stability in care arrangements?
- What are the attributes of respite models of care that result in wellbeing benefits for the child and/or the parent/caregiver?

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<sup>1</sup> 'Caregiver' is understood as an inclusive term that does not differentiate between the presence or absence of kinship ties between the child and the adult.

# METHOD

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## Scope

This evidence brief builds on the knowledge already captured by:

- an early draft of an evidence brief that was never completed, tentatively named Care Continuum – Emergency and Respite Care. The draft was developed in 2018, and it has some overlaps with this present evidence brief. The draft focused on respite care within the child protection and edge of care space in other jurisdictions, and stigma within the State care system;
- a report of findings from the Caregiver Survey, How well is Oranga Tamariki supporting its caregivers? published 11 September 2019 (Nielsen, 2019); and
- a report of findings from the UCB/OB Survey, Caregivers Raising Children with the Orphan's Benefit and the Unsupported Child's Benefit: A survey of caregivers, published 12 December 2019 (Oranga Tamariki Evidence Centre, 2019).

The literature search for this evidence brief was conducted by *Allen + Clarke* personnel using the following databases: Google Scholar, ERIC, ProQuest, PsycINFO, and Scopus.

Publication date parameters were set at January 2015 or more recent, with exceptions being:

- literature accessed via snowballing, where such literature provided unique evidence; and
- literature accessed in relation to models of care in other jurisdictions, cited in the early draft, which was published prior to 2015.

The literature relates to Aotearoa New Zealand, Australia, Canada; Republic of Ireland, United Kingdom, or the United States of America.

The United Kingdom Department for International Development (DFID) guidance on assessing the strength of evidence of individual studies guided the quality assessment, with AMSTAR 2 being used for the assessment of systematic reviews.<sup>2</sup> In this evidence brief, quality assessment was carried out for articles that contributed to four or more research questions ('key articles').

The DFID guidance calls the assessor to first categorise the study by research type and design, and then to assess the report against seven principles through a series of questions. The principles are:

- conceptual framing;
- transparency;
- appropriateness;
- cultural sensitivity;
- validity;
- reliability; and
- cogency.

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<sup>2</sup> For an in-depth explanation about these quality appraisal tools, see <https://www.gov.uk/government/publications/how-to-note-assessing-the-strength-of-evidence>; and <https://amstar.ca/Amstar-2.php>

Studies that were excluded from the scope of this evidence review were authored by undergraduate students whose principal purpose in writing was reflective.

## Developing an agreed list of inclusions

### The literature search

The initial search of the academic literature returned 2,092 articles. Table 1 shows the results, by search string. The initial search was conducted in Google Scholar. The four other search engines used provided either a very modest number of additional articles or no additional articles.

Table 1: Literature Search Results

Search string	Returns
child* OR youth wellbeing OR well-being "short break"	1,610
child* OR youth wellbeing OR well-being "respite care"	482
<b>TOTAL RETURNS</b>	<b>2,092</b>

In each case, the search string was accompanied by the following limitations:

- **Must include** at least one of the following terms: report, evaluation, review, evidence
- **Must not include** any of the following terms: dementia, "aged care"
- Publication date range: 2015 - 2020

### Scanning the returns

The results were reviewed in-situ, at abstract level, with approximately 150 promising articles then accessed in full-text.

Full-text articles were imported to NVivo (via Zotero), where they were scanned and coded to ascertain their relevance for addressing one or more of the five research questions.

During the scan, it was observed that many articles simply stated there to be 'benefits' of respite care, often accompanied by a statement to the effect that the benefits of respite care were well understood and accepted. Consequently, the search for 'evidence' of the benefits (for children, young people, and caregivers) sought either primary research articles, which presented research findings as evidence; or secondary citations, where articles cite primary research in support their of claims that respite care provides particular benefits. In this latter case, where a secondary citation is used, the original source has not been accessed in the development of this evidence brief.

Roughly 20 further articles were accessed in full-text, snowballing from scanned articles. Some of the newly-accessed articles were published prior to 2015. These were retained in the inclusions list where they provided evidence that had not been available through more recent publications.

### Narrowing the inclusions list

Five literature reviews are amongst the inclusions. Their reference lists were cross-checked against the scanned literature so that full-text articles could be excluded from the inclusions list, on the basis that relevant key findings are incorporated in one or more of the included literature reviews.



Following the scan, with 70 articles remaining, we identified seven articles (key items) that related to four or more of the research questions. We also identified 35 articles that related to just one or two research questions. These 35 papers were re-scanned to ascertain the value of their retention: those that added unique evidence were retained, whilst those that did not offer unique evidence were removed. With the agreement of Oranga Tamariki, the inclusions list was reduced by removing the least useful 20 items, which allowed for the protection of a small number of items that contributed unique evidence.

A further eight items were introduced as a result of the inclusion of material from the 2018 draft.

## Assumptions

This evidence brief has been developed from literature about populations of children and young people who experience respite care due to a variety of conditions. Some are welfare-involved, 'in care', or 'looked after'; some have disabilities; some have developmental, behavioural, or health issues – including some whose condition is classed as 'life-limiting'. Appendix 1 lists the primary literature used to develop this evidence brief, and it provides various attributes of each study, including the condition shared by the population in focus. This approach, of including literature beyond the welfare-involved population, assumes that the majority of the benefits of respite care are the same across these varied populations. The literature has provided the following observation, reported by Leake et al. (2019), regarding the U.S.

*An estimated 50% of children in foster care can be clinically diagnosed with emotional or behavioral problems (Greeson et al., 2011; Leslie, Hurlburt, Landsverk, Barth, & Slymen, 2004), and untreated trauma-related mental and behavioral health issues are the primary reasons for failed placements (Barth et al., 2007; Oosterman, Schuengel, Slot, Bullens, & Doreleijers, 2007).*

*Behavioral challenges not only lead to caregiver strain and turnover, but also placement disruptions (Brown & Bednar, 2006; Chamberlain et al., 2008; James, 2004), (2019, p. 286).*

If the U.S. context described above is similar to the New Zealand context, then the assumption is reasonable: many caregivers in New Zealand are likely to be caring for children whose needs step beyond the need for a home, with food and shelter – not to mention the trauma that many children are likely to experience from being separated from their caregiver(s). Thus, the needs for and benefits of respite care may be relatively uniform regardless of the condition experienced by the population in focus.

## Limitations

When considering the information provided in this evidence brief, it is important to recognise that, although the search of the literature was relatively detailed and extensive, it is likely that some research or reports that address the key research areas were not identified in the search, and are therefore not included in this report.

Furthermore, the quality of each study was assessed only for six of the articles that contributed to four or more research questions ('key articles').<sup>3</sup> This report also includes information from material which was not formally assessed for methodological robustness. We have also included information sourced from individual studies, which may be more subject to bias than research that collates findings across several studies and analyses the results as a whole. While we have attempted to

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<sup>3</sup> The seventh such article was of a type that did not lend itself to reliable assessment via either tool.

address these limitations by clearly indicating the source of information presented in this evidence brief, it is important that the information presented from non-systematic reviews or individual studies is interpreted with caution.

Most of the evidence included has been sourced from outside of Aotearoa New Zealand, primarily from the U.S. (n=15) and the U.K. (n= 8). Although the selected jurisdictions are broadly similar to Aotearoa New Zealand, care needs to be taken when generalising the findings to the unique cultural and environmental context of Aotearoa New Zealand.

# RESEARCH QUESTION 1

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## How is respite care provided in Aotearoa New Zealand and other jurisdictions, for children outside of or within the state care and protection system?

### Respite care trends

Many authors have noted that, although respite services for caregivers of care-experienced children is an entitlement in many jurisdictions, they can be very difficult to access. Such respite tends to be poorly planned, more often than not being sought and/or provided only as an emergency service. There is concern that this should not be the case. Instead, respite care should be planned and normalised, bearing in mind that there will be instances where emergency respite care is also required, and in which case urgency is paramount.

Aligned with the above, Baginsky et al. (2017) have noted that, in the U.K., satisfaction with the respite care service has declined, with only one-quarter of respite carers who responded to the survey rating the service a good or excellent, compared with one-third in 2014 (Lawson and Cann (2017) in Baginsky et al., 2017).

Further, a survey of caregivers and respite care services in the U.S. found that the most frequently reported limitation of respite care was the lack of respite care providers (Jedwab et al., 2020).

Similarly, the results of a survey of caregivers conducted by Oranga Tamariki, reported in 2019, stated that there was a lack of awareness of respite care being available, of when it could be taken, and that it could be requested rather than waiting for it to be offered (Nielsen, 2019). This presents an opportunity for Oranga Tamariki to refresh its respite care offering, to provide a consistent, world-class respite care service for its caregivers.

### Models of respite care

At the highest level, the literature reviewed for this evidence brief describes four models of respite care:

- **In-home respite care**, where a respite carer comes to the home of the child or young person, looking after them there. Care duration varies from an hour or so to overnight;
- **Centre-based respite care**, where a child or young person attends a centre along with other children or young people for all or part of the day;
- **Residential-based respite care**, where the child or young person temporarily relocates to a residential home overnight or longer. The residential home may be a private home, or a community facility; and

- **Residential respite care camps**,<sup>4</sup> where the child or young person (sometimes accompanied by other family members) participates, for few days to a few weeks, in a camp that has been designed to cater for a particular condition or need(s).

The findings from the evidence review are structured around these four models of care.

### **In-home respite care**

**In-home respite care** is where a respite carer comes to the home of the child or young person, looking after them there. Care duration varies from an hour or so to overnight. Within the care continuum, in-home respite care is not common, though it is sometimes available as part of a long-term care plan for foster carers of children who are in state care.

#### *In England, local authorities are obliged to provide short break services*

Local authorities in England have a legal duty to provide a 'short breaks' service for disabled children and their caregivers. A short break can range from a few hours to several days; and it can be provided in the child's home or in the home or facilities of the respite caregiver, which may be a service rather than an individual. In their information sheet about their services, Contact a Family (Contact), (an agency that provides respite care services), suggests families use home-based day care as a building block to prepare children for longer, away from home care (2018).

Within England, there is variability in how the short break model of care is provided. For example, the Contact information sheet advises that in some local authorities, the short break services model of care is accessible without a needs assessment; but in other local authorities the service is exclusively for children covered under the Chronically Sick and Disabled Persons Act 1970. They also note that the costs for respite care vary by local authority, with the income and savings of the caregiver often considered.

#### *In-home care in Aotearoa New Zealand is designed for elder and disability care*

A Ministry of Social Development publication (2019) for caregivers, indicates that in-home respite care services mainly focus on those caring for the elderly, and people with physical, intellectual and/or sensory disabilities. Qualifying cases may be entitled to support, such as cleaning, if the applicant is a Community Services Card holder.

New Zealand-based service providers that include respite care provision appear to be under-researched. If they are researched and/or evaluated, any outcome reports are not, by and large, readily available via the internet or through academic publications. A brief list of providers is attached as Appendix 2.

### **Centre-based respite care**

**Centre-based respite care** is where a child or young person attends a centre along with other children or young people for all or part of the day.

#### *Day foster care –Ireland*

Day foster care is an alternative form of foster care which provides struggling families with a support system in the community. It is a flexible service that allows children to remain in their own homes

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<sup>4</sup> Although this model of care is a subset of the 'Residential-based respite care' type, it is sufficiently distinct in the literature reviewed to warrant separate treatment in this evidence brief.

during the evenings and weekends, while receiving family-based care in the home of a foster carer during the day-time. This arrangement causes minimal disruption for the child and family, and reduces the trauma a child will experience in being separated from their family. Day foster care is seen as a preventative measure, allowing a family space and time to address issues, and safeguards against a child being placed in full-time care. Children benefit from the additional care and stimulation in the foster home, and caregivers can obtain practical help, advice, and support from the day-foster caregiver. (Houses of the Oireachtas, 2017).

### *Short break activities in England are fun-focused*

Examples of services that provide centre-based short breaks that do not include overnight stays are nurseries, playgroups, after school and weekend clubs, summer holiday play schemes, sports activities, music, art, and drama activities (Contact a Family, 2018). Some of these activities may be available universally, whilst others may be limited to children with defined needs.

### *Early childhood wrap-around services may protect vulnerable children and young people*

'Relief Nurseries' in Oregon aim to reduce child abuse and neglect amongst families of 'at risk' children. They provide wrap-around services to children and their families including early childhood education as a form of respite care (two afternoons per month for six months), home visits, caregiver education, and support through referrals to other organisations (Eddy et al., 2020). A randomised controlled trial conducted by Eddy et al. assigned 180 families to receive either the full service, or a reduced service that provided respite care and referrals to other services. Eddy et al. found that families receiving the full service had better outcomes. More families receiving the full service used the respite care services, and they made more use of that service than the comparison group. At the end of the two-year study, families assigned to the full service reported higher levels of social support than families assigned to the 'respite only' group; with higher social support considered protective against abuse and neglect.

The "Flying Start" programme was piloted in Wales in 2006/07, and launched in 2007/08. This wrap-around service (which includes respite care) aims to make a decisive difference in the life chances of children aged four years and under living in areas that are described as "seriously disadvantaged". The programmes focused on language, cognitive, social, and emotional development, physical health, and the early identification of high needs (White & McCrindle, 2010). All children living in the designated areas were entitled to attend, without further means testing. An evaluation of the programme was commissioned in 2007 to assess the effectiveness of integrated services at improving life chances. This found the programme to be effective, commenting that the programme "struck the right balance between providing prescriptive guidance and allowing local flexibility and prompted multi-agency approaches to delivery" (White & McCrindle, 2010, p. v).

## **Residential-based respite care**

**Residential-based respite care** is where the child or young person temporarily relocates to a residential home overnight or longer. The residential home may be a private home, or a community facility.

### *Support Foster Care (U.K.)*

Support Care is a time-limited preventative intervention for families who are at risk of children being placed in out-of-home care. Families are matched with a support carer who provides short-break respite for a child, and non-judgemental support for caregivers.

Children typically spend one or two weekends each month at the home of their support carer, over nine to twelve months, though respite resource is said to be flexible and can be tailored to meet family needs, also allowing for day or evening breaks (The Fostering Network Wales, ND).

An intervention plan is agreed by the caregivers, children, and social workers, to identify goals and outcomes that will be worked towards throughout the intervention. Goals are set for both the caregivers and children. Caregivers are often directed to additional support services, such as parenting skills, and receive guidance from their support carer during the service. Children are helped by their support carer to reach goals that may include social communication skills, or behavioural or developmental milestones (e.g., toileting) (Roberts, 2016).

Support foster carers are subject to the same regulations and standards as mainstream foster carers, and local authorities separate their pool of support foster carers from their mainstream long-term foster carers to ensure resource for support care is not diverted from longer-term foster carers (Greenfields & Statham, 2004; Williams, ND).

Established support care schemes report that only 2% of children whose families received support care intervention will eventually move to out-of-home care (The Fostering Network Wales, ND).

### *Considerations*

Because it is a time-limited service, children eventually stop visiting the homes of their support foster carers. The need for the time-limited nature of the intervention being clear to the children involved (though not always possible due to age of a child), and the planning of ending sessions, was expressed by both support foster carers, and caregivers receiving the intervention. However, even when these conditions were met, the end of children's involvement with the service and with their support foster carers can be emotionally challenging for children. Some children interpreted the end of the service in terms of a loss, or with sadness. If no ending sessions were facilitated, service ending was interpreted by children with feelings of confusion and rejection (Roberts, 2015).

As this service is not community-based and is time-limited, support is effectively withdrawn when the service ends, regardless of whether or not there is a need for continued support. Caregivers who face continued stressors (e.g., mental health issues) past the end date for service completion are not able to access continued support foster care and are offered alternatives such as voluntary state care for their children (Roberts, 2016).

Local authorities implementing support foster care noted legislative difficulties as to where the service fits in the framework of state care. Most local authorities did not record children accessing the service as under state care, and instead applied a simplified version of requirements (The Fostering Network Wales, ND).

Access to support foster care in some local authorities required strict conditions to be met. For example, families were required to be accessing at least three other support services, and to have a social worker appointed to be eligible for support foster care (The Fostering Network Wales, ND).

### *Safe Families For Children (U.S. and U.K.)*

Safe Families is a community-based, child-hosting service organised primarily by local churches and NGOs, through which Caregivers can voluntarily have their children placed with a Host Family in a time of crisis or need. Placements vary in length, from a day to a year or more (Little et al., 2017).

Host Families undergo extensive training, home inspections, and background checks before being approved as Hosts. Host Families receive no payment for caring for children through this service; it is all voluntary (Little et al., 2017).

The program is often overseen by a private child welfare agency, which provides the professional resources necessary to ensure the safe and efficient operation of the model. That private agency is responsible for recruiting, training, and supporting volunteers who provide direct help to families in crisis (Little et al., 2017).

Throughout the hosting placement, Case Coaches and Family Friends offer support to families using the service. The Case Coach role is to facilitate the relationship between the child's family and the Host family during placement, to ensure child well-being, and that the needs and issues of all involved are communicated. Family Friends do not host children, but befriend the caregivers of the child being hosted to provide community support, guidance, and practical assistance (e.g., with job applications) (Little et al., 2017).

The placement allows temporary respite from childcare responsibilities that enables caregivers time to achieve certain goals such as improving parenting skills, gaining employment, or finishing a training course. In the case of sole caregivers who have no support structure, Safe Families are also called upon to provide emergency placements when, for example, a caregiver is hospitalised and temporarily unable to care for their children (Little et al., 2017).

Child hosting is much akin to foster care, though during placement, parents maintain full parental and legal rights of their child. In some U.S. states, parents are required to consent to emergency medical rights for Host parents. Retention of parental rights means parents feel safe to ask for help and do not fear losing their children while trying to achieve stability in the home. Without this fear, parents are more likely to seek help at an early stage, improving the chances that the combination of Host Family placement and Family Coaching/parental support will achieve stability in the home, and ultimately, reunification of children with their parents (Little et al., 2017).

### ***Better Outcomes for Children***

The aim of Safe Families for Children (SFFC) is family reunification in a home that is more stable and healthy. Over 90% of children hosted through SFFC have been successfully reunited with their biological families in comparison with just over 50% of those who enter state-led child welfare agencies (Gita Cugley & Associates Consulting, 2018, p. 23).

SFFC has lower levels of entry/re-entry into the state-led child welfare system, where of almost 20,000 children hosted by SFFC, only 2% have needed referrals into the state system. This is in contrast with those who have spent time in the state-led welfare system and been reunited with their families, where nearly 20% of those will be re-referred to the state system (A. Brown, 2015).

SFFC is able to reunite families much quicker than state-led welfare foster care. The average length of time for hosting a child in SFFC is 29 days. Children who are placed into state-led foster care will spend an average of 702 days in an out-of-home placement (A. Brown, 2015).

Costs to host a child vary depending on whether a Chapter of SFFC is served primarily by volunteers or if it has paid staff. Chapters aim to be led by volunteers to reduce costs, though may involve paid staff during initial establishment of a new Chapter. On average, it costs \$1,500 per child served through SFFC and is mostly (some proportion through state grants) or entirely privately funded. Children served through the state welfare system cost taxpayers an average of \$25,000 per year (A. Brown, 2015).

### *Issues in implementation*

Because the SFFC model is voluntary, it requires a supportive legal and regulatory environment. In some U.S. states, the model receives opposition because it poses an alternative to the traditional state-run system. Other U.S. states have fully embraced the model as an essential partner for the protection of children, offering effective solutions to reduce the number of children entering the state care system, freeing up the resource of state care services for high-need cases (A. Brown, 2015).

In the U.K., where the model has recently been introduced, establishing the legal status of Host Families proved somewhat difficult, with a number of local authorities disagreeing on the legality upon which children are hosted in the SFFC model (Little et al., 2017).

Implementation of SFFC in the U.K. has been in a manner that is more embedded within the state care system than in the U.S., and is managed by the local authorities who also manage placements within the state care system. Better systems management to give timely matching of a family requiring SFFC support with a Host Family was identified as a key factor limiting the realisation of the potential of the SFFC model within the U.K. context (Little et al., 2017).

### *'Edge of care' services aim to keep children and young people with their families*

An evidence scope conducted in early 2015 (Houses of the Oireachtas, 2017) explored the role of short-term stays in residential care for adolescents who are at risk of entering care. The evidence scope highlighted numerous organisations and models of care in use throughout Ireland to provide 'edge of care' respite services that aim to prevent the adolescent from being separated from their family and keeping families together.

### **Informal and formal kinship support**

In most families, whether there are significant difficulties or not, having the opportunity to spend time apart when children go to a grandparent, aunt or uncle for a weekend or during school holidays, can provide a welcome breathing space within family life for parents and children. For some, this might prove essential during times of difficulty, illness or acute family stress (Dixon et al., 2015, p. 47). Dixon et al. note that when a 'welcome breathing space' transforms into something 'essential', kinship caregivers are comparatively poorly supported, receiving fewer resources and having poorer access to specialist services compared to non-kinship caregivers. In response, organisations (sometimes charities) provide services that aim to prevent breakdown between the young person and their kinship caregiver. One example was the provision of a fostering social worker who supported the adults caring for the adolescent, where the young person was not living with their primary family. Dixon et al. report that a local authority provides a range of services aimed at preventing the young person entering care, including respite through 'short breaks'. They highlight a programme, *Safe Families for Children*, founded in Chicago in 2003 through a church community and operating in 65 cities across the U.S. Volunteers are trained, vetted, and matched with families who have at least one child under 10 years of age. The short-break service duration ranges from a single night to 28 days (2015).

### *Local authorities in the U.K. have statutory obligations to provide 'short break' services for those caring for children and young people with disabilities*

Dixon et al. (2015) note that respite care for children and young people with disabilities is well developed in the U.K., with local authorities having statutory obligations in this respect. Services are typically arranged around therapeutic activities and may be provided through foster care or in a residential facility, with some local authorities providing both.



It has been found that families with children who have complex medical needs tend to prefer short breaks with an agency rather than in-home respite care, as this model afforded families the spontaneity and freedom that they sought (Macdonald and Callery (2004) in Edelstein et al., 2017).

U.K.-based respite care agency Contact a family (Contact) advises parents that overnight breaks can be arranged in the child's own home as an 'overnight sitting' service; which can include 'hospice at home' services for children requiring this level of care. Longer breaks tend to be in a residential home, a special unit in a hospital, or a hospice; and these typically offer indoor and outdoor activities as well as providing nursing care (Contact a Family, 2018). Contact notes that some services are 'universal' meaning that families can apply without needing to meet the definitions under the Chronically Sick and Disabled Persons Act 1970. They further note that most users are at least in part charged for the services provided.

In Aotearoa New Zealand, the Ministry of Social Development (2019) advises parents that facility-based respite care services are free if the child meets the eligibility criteria; and that there is funding available for carer support, enabling the reimbursement of some costs where the principal caregiver and/or the person being cared-for, and/or the respite carer qualify.

### *The Mockingbird Family Model*

Originating in the U.S., this model has been trialled in the U.K., with an evaluation of that trial reported in 2016 (McDermid et al., 2016). The Mockingbird Family Model (MFM) (Northwest Institute for Children and Families, 2007) is a foster care model that is designed to improve the safety, well-being, and stability of care of children in foster care, while also aiming to improve retention of foster carers through peer support and respite care availability.

Foster families are organised into a "constellation" of six to ten families, with the aim of establishing an extended family and community. Each constellation is supported by an experienced and licensed support caregiver who is the "Hub Home Parent". This Hub Home Parent supports children and parents within the constellation when needed, including relationship-based respite care, peer mentoring, and organising monthly support group meetings and social activities for all members of the Constellation Family. Links with a child's biological family can be maintained through their involvement within the Constellation Family and their activities. The constellation structure itself is implemented by a public or private organisation responsible for case management of the foster children and for licensing supervision to foster parents.

Foster parents within a constellation can call upon the Hub Home Parent for emergency or respite care whenever needed. Where this model deviates from most other programmes is that the respite care is relationship-based; foster children within the constellation have familiarity with the Hub Home Parent due to the regular contact with them during the constellation's (at least) monthly outings and events. The language used with the children is normalised: they go for a sleepover, as opposed to being sent away because a parent needs respite. Sleepovers can be planned or in response to an emergency, and may be requested by the child. Moreover, the very act of the sleepover or respite is normalised and destigmatised in that it is with a member of the child's Constellation Family with whom they have established a relationship (The Mockingbird Society, 2010, p. 20). It is no longer viewed as a last option emergency response where a child is sent to a stranger's home. Children report the Hub Home being like a kind of second home, while foster parents report a sense of relief that they don't have to worry about the standard of care offered to their child while in respite care (McDermid et al., 2016).

Foster parents report much higher usage of respite care through the MFM than standard foster care settings in both the U.S. and the U.K. (McDermid et al., 2016; The Mockingbird Society, 2010), with

parents suggesting it is easier to access respite through the Hub Home Parent than through more standard service routes. Foster parent retention is also seen to be higher through the MFM than in standard foster care settings (McDermid et al., 2016; The Mockingbird Society, 2010).

In addition, by intentionally modelling aspects of an extended family, MFM foster children are provided with a community of peers who have similar experiences, from whom they do not feel the need to hide their foster care status. This allows them to build lasting peer relationships and community connections, creating a sense of belonging, acting to enhance their well-being, and reduce the effects of stigmatisation associated with being a foster child (Northwest Institute for Children and Families, 2007; The Mockingbird Society, 2010).

### *A model of care trialled in the U.K. has revealed limitations*

The Fostering Network includes the provision of one or two overnight stays per month, for 6 to 12 months, as the respite aspect of a broader family support package that aims to support families that are experiencing a crisis and are at risk of becoming separated. The service developed a network of 'part-time' foster carers. A limitation of the model, identified in a review of the service, was that the need for close monitoring of the families to protect vulnerable children made families uncomfortable, despite the service stressing non-judgemental partnership relationships between the service providers and the families receiving respite care (Roberts, 2016).

### **Residential respite care camps**

**Residential respite care camps** are where the child or young person (sometimes accompanied by other family members) participates, for few days to a few weeks, in a camp that has been designed to cater for a particular condition or need(s).

The literature describes camps that have been established for a range of participants, including just children and/or young people; or expanding this to include other members of their household, such as siblings (who could be foster siblings), and/or caregivers (who could be foster carers or kinship caregivers). Camp participants have a shared experience that qualifies them to attend camp. In most studies reviewed for this evidence brief, this 'shared experience' was medical in nature (Flynn et al., 2019; Kelada et al., 2020; Luzinat et al., 2020; Neville et al., 2019) but one study focused on a camp run for children who are cared for by their grandparent(s) (Dare et al., 2020).

Camps tend to have a staff with a wide range of specialisations, including medical where appropriate. Camp activities tend to be of a type that build bonds and/or strengthen existing relationships between participants within their family groups and between individuals or family groups. Activities are designed to extend participants physically and emotionally to drive development.

It has been found that "social interactions and peer binding through camping can be beneficial from improving skills such as relationship building, self-control, self-help, communication, and promoting positive attitudes," (Flynn et al., 2019). Research into the efficacy of respite care camps, some longitudinal, has shown the gains experienced by camp participants to be retained in the medium term, and that participants who attend camp annually continue to build their skills and wellbeing over time.

# RESEARCH QUESTION 2

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## What is the evidence for respite care (formal and informal) being beneficial to the wellbeing of children and young people?

A range of benefits were identified in the 17 items that addressed this research question. There were four benefits identified by six or more authors. Below, these benefits are individually synthesised, with the most frequently mentioned benefit addressed first. A list of less frequently mentioned benefits then follows.

### Socialisation or addressing social isolation

#### *Stresses associated with stigma may be reduced through respite care*

Residential respite care can provide children and young people a chance to develop friendships with peers who are in similar situations. Through the residential setting, the child or young person learns or reinforces their knowledge that they are not alone in their experience (Analytis et al., 2020; Dare et al., 2020), which is reported to reduce stigma-associated stress (Gillard et al., 2011).

Through a mixed-methods interpretive case study based at a summer camp throughout 2007 and 2008, Gillard et al. conducted focus groups (n=19 participants) and individual interviews (n=17) with young people who had an HIV/AIDS diagnosis. According to the young people, the shared experience of a common diagnosis not only situationally removed the threat of stigmatisation, but it also helped them recover from the effects of everyday stigmatisation, because they could relax their guard.

#### *Improved socialisation has been observed*

Respite care can provide opportunities to learn new social skills, improving socialisation (Analytis et al., 2020; Contact a Family, 2018; Nack, Liddicoat, Franzen, Scheder and King (2018) in Flynn et al., 2019; Davies et al. (2004) in Hill, 2016; Kelada et al., 2020; McGrath, 2019; Neville et al., 2019; Short-DeGraff and Kologinsky (1987), Starkey and Sarli (1989), Prewett (1999), Tarleton and Macaulay (2002), and McConkey et al. (2004) in Spruin et al., 2018; Welch et al., 2014; White & McCrindle, 2010).

For example, in their evaluation of short-break schemes, Spruin et al (2018) noted that children benefit from:

*improved well-being through social contact ... improved ability to form and maintain relationships, increased interaction with peers through participation in mainstream leisure activities ... [and] strengthened family relationships through an increased sense of well-being, (Spruin et al., 2018, pp. 3–4)*

Improved socialisation is frequently related to respite care through residential camps (Analytis et al., 2020; Dare et al., 2020; Flynn et al., 2019; Gillard et al., 2011; Kelada et al., 2020; Neville et al., 2019). The effect is understood to occur through the naturally immersive social environment, which helps children practice and improve their prosocial skills (Garst, Browne and Bialeschki 2011 in Flynn et al., 2019).

In their findings from a longitudinal study, Flynn et al. have observed that improved socialisation is greatest at Year 1, with smaller improvements year-on-year amongst children with special needs who attend annual respite care camps. They also reported that improved socialisation was the second most common benefit to children attending respite care camps, according to parents.

## New experiences or skills

### *Enhanced physical health has been observed through residential camps*

Particularly through residential camps, enhanced physical fitness and physical skills attainment have been observed (Kelada et al., 2020; McGrath, 2019; Spruin et al., 2018). In studies of children with a cancer diagnosis, improved physical functioning between the first day and last day of respite care camps has been found (Withycombe et al. 2018 in Spruin et al., 2018) with improvements still evident at nine months follow-up (Li et al. 2013 in Spruin et al., 2018). Another study reported that children and young people returning to camp year-on-year continued to improve their physical functioning (Wu et al. 2016 in Kelada et al., 2020).

### *New skills can relate to many things*

Some authors note that the activities provided for children and young people during respite care present opportunities and physical challenges that might otherwise be unavailable to them (Analytis et al., 2020; Borenstein & McNamara, 2015; Contact a Family, 2018; Cotterill 1995 in Cotterill et al. 1997 in McGrath, 2019; Davies et al. 2005 and McConkey et al. 2004 in Spruin et al., 2018; Welch et al., 2014). Other skills are more nuanced, such as becoming more independent (Contact a Family, 2018; Cotterill 1995 cited in Cotterill et al. 1997 in McGrath, 2019; O'Rourke et al., 2019; Welch et al., 2014), learning to deal with trauma (Dare et al., 2020), or attitude development (Gillard et al., 2011).

For example, a study from Australia, exploring the benefits to children and caregivers of a respite care camp designed for children being cared for by their grandparents, reported that grandparents considered the camps to provide an environment that enabled their grandchild to:

*emotionally 'unblock' traumatic memories through the sharing of experiences in a safe and supportive camp environment; developing resilience, confidence and self-esteem through participation in challenging activities; and making new friendships (Dare et al., 2020, p. 1)*

Also from Australia, a study exploring the outcomes of a camp for children with acquired brain injury (ABI) found that:

*Across all ages, [camp] participants spoke of being supported by volunteers and families to do activities which challenged them. Young people with an ABI spoke of feeling supported to face the challenging aspects of life with ABI (Analytis et al., 2020, p. 8).*

## Resilience

### *Resilience can be built and enhanced through respite care camps*

Respite care camp experiences, such as new activities, physical challenges, and building relationships with new people, are reported to collectively result in enhanced personal resilience (Borenstein & McNamara, 2015; Dare et al., 2020) and self-efficacy – especially through 'adventure therapy', where participants engage in challenging activities (Neville et al., 2019).

Through a longitudinal study, using a fixed linear effect model to examine data from 2007 to 2013, Flynn et al. (2019) found that participants developed significantly higher social skills, including self-control and self-help, through respite camps. The authors posit that it was through this improved

resilience that children and young people more frequently engaged appropriately with others. Similarly, improved self-control and use of self-help mechanisms – such as coping with bullying or conflict – have been observed (Nicholas et al. 2009 in Analytis et al., 2020; Flynn et al., 2019; Gillard et al., 2011; Kelada et al., 2020). Learning new skills gave children and young people confidence and a sense of achievement and independence (Gaskell 2007 and Nicholas et al. 2009 in Analytis et al., 2020).

Finally, increased independence has also been highlighted as a benefit of respite care (Gaskell 2007 and Nicholas et al. 2009 in Analytis et al., 2020; Kelada et al., 2020; O'Rourke et al., 2019; Spruin et al., 2018).

## Self-esteem

### *Respite care camps may enhance self-esteem*

Attending a residential camp where participants have a common shared experience has been found to be positive for the self-esteem of many children and young people (Analytis et al., 2020; Borenstein & McNamara, 2015; Dare et al., 2020; Flynn et al., 2019; Kelada et al., 2020; Dawson, Knapp, Farmer 2012 and Wu et al. 2016 in Neville et al., 2019; O'Rourke et al., 2019; Welch et al., 2014). This appears to be because a condition that is frequently perceived as an attribute of 'otherness', or of being an 'outsider' is instead the norm. This normalcy is then coupled with the achievement of challenging activities. Analytis et al. refer to this experience as a sense of safety to be oneself.

On the other hand, Kelada et al. (2020) report in their literature review that study results in this respect are mixed. Some studies have found no change in self-esteem between three measures (pre-camp, immediately post-camp, and at follow-up: four to six months post-camp) (Stein 2017 in Kelada et al., 2020). In contrast, others have found improved self-esteem from pre-camp to one to three months post-camp (McGrane in Kelada et al., 2020); and another study showed sustained improvements in self-esteem, with self-esteem being positively related to the number of years the child had been attending camp (Wu et al. 2016 in Kelada et al., 2020).

## Other benefits to children and young people

Other benefits to children and young people through respite care were identified.

- Brief but frequent overnight respite care can expose young people to a positive, safe, and supportive environment (Dixon et al., 2015).
- Grandparent caregivers consider respite camps to provide a safe place in which their grandchildren can come to terms with trauma (Dare et al., 2020).
- Children have reported the respite camp environment to be more supportive than either the home or school environment (Neville et al., 2019).
- Children have described their observation and happiness that non-judgemental support is provided by camp staff (Kelada et al., 2020).
- Regular daytime respite care for infants and toddlers may provide “an extra set of eyes” on at-risk youngsters (Klein et al., 2018).
- Improved family relationships and interactions (Kelada et al., 2020; McGrath, 2019; Spruin et al., 2018), especially between young people and their carers (Borenstein & McNamara, 2015; Neville et al., 2019).

- The building of positive relationships with other adults (Klein et al., 2018; McDermid et al., 2016; McGrath, 2019; Spruin et al., 2018).
- Relieving stress (Baginsky et al., 2017; Borenstein & McNamara, 2015; Gillard et al., 2011).
- Improved overall quality of life (Kelada et al., 2020; Neville et al., 2019; O'Rourke et al., 2019).
- Reduced depression or anxiety (Dare et al., 2020; Neville et al., 2019).
- Emotional development (Spruin et al., 2018; White & McCrindle, 2010).
- Physical development (McGrath, 2019).
- Having a routine (in contrast to chaos) (Klein et al., 2018).

# RESEARCH QUESTION 3

## What is the evidence for respite care (formal and informal) being beneficial to the wellbeing of the parent/caregiver?

A broad range of benefits were identified in the 24 items that addressed this research question. There were seven benefits identified by six or more authors, and four benefits identified by five or less authors. Below, the seven benefits mentioned most frequently are individually synthesised, with the most frequently mentioned benefit addressed first. The remaining benefits are listed collectively.

### A 'rest' or 'break' is provided

There is consistency in the evidence regarding benefits of rest for caregivers. Through respite care, caregivers:

- focus on their personal needs (Borenstein & McNamara, 2015; Dixon et al., 2015; Hill, 2016; Jedwab et al., 2020; McGrath, 2019; Robertson et al. 2011 in Norton, 2016);
- rest (Borenstein & McNamara, 2015; Harper et al., 2013; McGrath, 2019; Norton, 2016; Spruin et al., 2018);
- relax (Harper et al., 2013; Luzinat et al., 2020; Norton, 2016; Spruin et al., 2018);
- do something memorable, such as attending a social event or taking a vacation (Borenstein & McNamara, 2015; Jedwab et al., 2020; Klein et al., 2018; McKiernan et al., 2020; Chan and Sigafos 2001 in Spruin et al., 2018);
- get relief from fatigue (Hill, 2016; McGrath, 2019; McKiernan et al., 2020; Remedios et al., 2015);
- recharge (Borenstein & McNamara, 2015; Harper et al., 2013; Pope et al., 2020) or recoup their energy (Dixon et al., 2015);
- engage in everyday activities that might otherwise be too difficult to undertake (Hill, 2016; Olsen and Maslin-Prothero (2001) in McKiernan et al., 2020; Spruin et al., 2018); and
- sleep (Hill, 2016; McGrath, 2019; McKiernan et al., 2020).

### Stress is reduced

#### *Respite care relieves stress amongst caregivers*

There is considerable evidence that respite care reduces stress for caregivers, (as illustrated though the extensive list of citations that follows) (Cowen and Reed 2002 and Meadowcroft and Trout 1990 in Baginsky et al., 2017; Hartley in Borenstein & McNamara, 2015; Forde et al. 2004 in Edelstein et al., 2017; Owens-Kane 2007 in Goemans et al., 2018; Harper et al., 2013; Wood 2010 and Sherman 1995 in Hill, 2016; Leake et al., 2019; Madden et al., 2016; Brown, Moraes and Mahew 2005, Framer, Lipscombe and Moyes 2005 in McDermid et al., 2016; Chan and Sigafos 2001, Cowen and Reed 2002, Strunk 2010, Nankervis, Rosewarne and Vassos 2011, Norton et al. 2016, Mullins et al. 2002, and Chapman 2013 in McGrath, 2019; Meltzer et al. 2004 in O'Rourke et al., 2019; Chapman 2013 in Spruin et al., 2018; Strunk 2010 and Harper 2013 in Whitmore, 2016).

Notably, the evidence for respite care reducing stress, cited above, exclusively rises from secondary citations: new evidence has not been encountered. Consequently, the relationship between stress-reduction and respite care can be considered to be proved.

However, an older study found that although respite care reduced stress and depression amongst caregivers, the decrease for was not maintained in the long term, with parenting stress returning to their previous levels within six months (Mullins et al., 2002). This finding suggests that respite care that aims to reduce caregiver stress cannot be considered a 'single dose cure'. As Mullins et al. state: "stress associated with parenting ...is only temporarily ameliorated," (2002, p. 134).

### **'Family time' is available to the family**

#### ***Out-of-home respite care may allow caregivers to spend more time with other members of the family***

When the needs of one child or young person within a household consume caregiver energy disproportionately, having that child or young person spend time in respite care provides the caregiver with an opportunity to invest increased energy into other household members. This is considered to benefit the caregiver as well those who are the recipients of extra attention from the caregiver (Borenstein & McNamara, 2015; Nankervis et al. 2011 and Damani et al. 2004 in Dixon et al., 2015; Hill, 2016; McGrath, 2019; McKiernan et al., 2020; Beresford 1995 in Spruin et al., 2018). Indeed, "respite care may be one of the strongest stress relievers for families" (Ruble and McGrew 2007 and Tehee et al. 2009 in Harper et al., 2013). Siblings have also described how respite care allows opportunities for them to get more of their parent's time (McGrath, 2019).

#### ***Family-based respite camps also provide quality family time***

Families spending time together in a purposefully designed supportive camp environment is another way that caregivers can benefit from 'family time' respite care services (Kelada et al., 2020; Luzinat et al., 2020). In their study of respite care camps designed for families that include a child with cancer, Kelada et al. found that, for many families, the camps provided an opportunity for the family unit to reconnect. Similarly, in a study of respite camps for families that include a child with disabilities, McGrath (2019) reported that parents described the camps as a source of hope, whilst siblings of the disabled child reported that the camps allowed them to get more attention from their parents.

### **Improved family functioning**

While 'family time' (discussed above) is about the act of families spending quality time together, improved 'family functioning' is a possible outcome from 'family time', such as through improved day-to-day functioning (Mullins, Aniol, Biyd, Page and Chaney 2002 in Norton, 2016); or simply regrouping and reconnecting as family unit (Hill, 2016; Pope et al., 2020).

#### ***Parenting education, as part of a broad respite care service, can improve family functioning***

Beyond enjoying 'family time', family functioning may be improved through parenting education provided to caregivers as part of a broader respite care programme (Klein et al., 2018). An early childhood care programme in the U.S. which operates in part as a respite service, not only provides care for the infants and pre-schoolers, but also provides parenting training, which is described as "empowering" (Klein et al., 2018). Similarly, the evaluation of the Ruchazie Family Centre in Scotland (Lucas & Gadda, 2018), which also provides respite services for families with very young children, found that parents learned new skills and gained confidence, leading to improved family functioning.

#### ***Family-based respite care camps can enable improved family functioning***

Respite care "can have a positive impact on the family as a whole," (Spruin et al., 2018); and more specifically on family functioning (McDonald and Callery 2004 and Chan and Sigafos 2001 in



McGrath, 2019), “allowing families to get along better, to spend time together and do a wider range of activities,” (Joyce et al. 1984, Marc and MacDonald 1988, McConkey et al. 2004, and Mannan et al. 2011 in McGrath, 2019). Through fun and relaxation, interactions between family members were observed to improve, resulting in positive changes in the family unit and decreased parental distress and worry (Luzinat et al., 2020).

## **Mental health is improved**

### ***Mental health is supported by respite care***

Parents have reported that respite care provides emotional relief to the household – including other children (Davis et al. 2004, Swallow et al. 2011, and Thomas and Price 2012 in Edelstein et al., 2017). This theme is continued by Klein et al. (2018) who reported that focus group participants observed that parents use respite care to “regroup emotionally”.

In a pre- and post- test concerning out-of-home respite care, caregivers reported significant improvement in mental health (Remedios et al., 2015); and psychological distress levels were reported to significantly decrease following respite care (Mullins et al. 2002 in Norton, 2016). Psychological wellbeing was improved (Mullins et al., 2002); and respite care has been advocated to help caregivers to “heal after a particularly traumatic placement or disruption” (Pope et al., 2020).

Postnatal depression has also been reported to be alleviated through respite care (White & McCrindle, 2010).

### ***Respite care can reduce caregiver anxiety***

Respite care has been shown to reduce caregiver anxiety (Barker et al. 2011, and Dillenberger and McKerr 2011 in Harper et al., 2013; Mullins et al., 2002). Mullins et al. reported that a significant decrease in anxiety was apparent when caregivers were assessed for anxiety pre- and post- respite care, with the reduction maintained at follow-up six months later.

## **Caregiver distress or depression may be reduced**

‘Caregiver distress’ relates to the burden or rigors of caregiving, either as a parent or as a foster parent. While it may be considered a subset of ‘stress’, in the literature it is frequently associated with depression, unlike ‘stress’. It is described as ‘objective strain’, which disrupts family routines and may be a financial burden, in contrast to ‘subjective strain’, which concerns the feelings and emotions associated with caregiving, such as anxiety, guilt, and fatigue (Angold et al. 1988 and Sales, Greeno, Shear and Anderson 2004 in Leake et al., 2019).

### ***Respite care may alleviate objective strain and depression amongst caregivers***

Distress and depression are frequently grouped, and stated to be alleviated by respite care (Collins et al., 2020; Nankervis et al. 2011 and Damani et al. 2004 in Dixon et al., 2015; Madden et al. 2016 and Owens-Kane 2007 in Goemans et al., 2018; Chan and Sigafos 2001, Cowen and Reed 2002, Whitmore 2016, Strunk 2010, Nankervis, Rosewarne and Vassos 2011, Norton et al. 2016, Mullins et al. 2002, and Chapman 2013 in McGrath, 2019; Mullins et al., 2002).

Overnight respite care has been associated with reduced parental stress as measured through an unidentified depressive scale (Meltzer et al. 2010 in Edelstein et al., 2017).

Respite care camps that focus on the household unit, rather than only on the child, were noted to alleviate parental distress (Luzinat et al., 2020).

However, there are contrasting findings: access to respite care has not consistently been associated with reduced objective strain (Leake et al., 2019). Further, Mullins et al. (2002) have reported that although pre- and post- testing has shown depression to be alleviated by respite, this was not sustained long term, with depression returning to pre- respite care levels within six months.

## **Marital quality is improved**

### *Quality time with one's partner is enabled*

Out-of-home and overnight respite care can be especially beneficial to marital quality, providing the caregiver with an opportunity to spend quality time with their partner without the demands of caring for a child or young person (Borenstein & McNamara, 2015; Buckner & Yeandle, 2017; Steele 2002 in Hill, 2016; McGrath, 2019; McKiernan et al., 2020; Harper et al. 2013, and Kersh et al. 2006 in Norton, 2016; Beresford 1995 in Spruin et al., 2018).

## **Other benefits parents and caregivers derived from respite care**

Other evidence of benefits to parents and caregivers through respite care include:

- Family camps for respite are useful for reducing the sense of isolation experienced by some caregivers (Analytis et al., 2020; Borenstein & McNamara, 2015; Kelada et al., 2020; Lucas & Gadda, 2018; Luzinat et al., 2020);
- Peer groups that endorse sharing practical advice and knowledge can result in increased confidence and self-esteem (Korver, and Bashore and Bender in Kelada et al., 2020; Luzinat et al., 2020; McKiernan et al., 2020; O'Rourke et al., 2019; White & McCrindle, 2010);
- Caregivers have reported improved quality of life through the provision of respite care (Edelstein et al., 2017; McGrath, 2019; Remedios et al., 2015); and
- Respite services that are non-judgemental are beneficial for the self-esteem of the caregiver (Kelada et al., 2020; Luzinat et al., 2020).

# RESEARCH QUESTION 4

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## What is the evidence for respite care (formal and informal) contributing to stability in care arrangements?

A small amount of evidence was described in the 12 items that addressed this research question. There were two themes identified by six or more authors. Below, those two themes are individually synthesised, with the most frequently mentioned aspect addressed first.

### Preventing placement breakdown

#### *Kinship carers (often grandparents) considered respite to be 'imperative'*

There is evidence that using respite services can be a means to preventing placement breakdown where grandparents are the caregivers. Grandparents have commented that the value of respite could not be overstated: it made the difference between continuing to provide care or to stop (Borenstein & McNamara, 2015). In the same study, a service provider estimated that 50 percent of kinship placement breakdowns were attributable to the inadequate provision of respite care. In this context, a service provider considered respite care to be a support for the emotional wellbeing of the grandparent caregiver, without which the quality of care provided may not be any better to that from which the child was removed.

#### *A U.K. trial of the Mockingbird Family Model shows the strength of respite in preventing placement breakdown*

In their Year 2 evaluation of the Mockingbird Family Model (MFM) trial, McDermid and Baker (2016) highlighted the MFM as facilitating conditions that improve placement stability, with an important condition being the accessibility of respite care. The ease with which caregivers can access respite care at the times and for the timeframes they sought, and with respite carers known to the caregiver and the child were important features. During the MFM trial, 4% of placements broke down, compared to the regional average of 8%. The social networks created through MFM participation have also been associated with placement stability (Sinclair et al. 2007 and Murry, Tarren-Sweeny and France 2011 in McDermid et al., 2016), with peer support having been shown to decrease foster carer stress (Luke and Sebba 2013 in McDermid et al., 2016). The evaluation concluded that the MFM contributes to improved placement stability.

#### *Caregiver strain is associated with placement instability*

There is some evidence that caregiver strain, emotion toil, and burnout are associated with placement instability (Geiger et al., 2013; Farmer 2005 in Leake et al., 2019). This point needs to be considered along with the evidence above (see Research Question 3, themes concerning stress and also distress) that respite care can alleviate caregiver strain, noting also that respite care is not a one-dose cure, but an ongoing treatment where regular top-ups are necessary in order to achieve the desired effect. McGrath is instructional on this point.

*Regular access to a high-quality respite service has also been shown to positively impact the caregivers ability to continue in their role as carer (Mansell and Wilson 2009, Wilkie and Barr 2008, and Collins et al. 2014 in McGrath, 2019).*

Brown and Bednar (2006) reported extensively on this point, highlighting earlier research linking placement breakdown to the lack of support provided to caregivers. Respite care was an important element of the support considered necessary to prevent caregiver burnout and placement disruption (Berrick 1998, Scannapieco and Hegar 2002, Butler and Charles 1999, and Seaberg and Harrigan 1999 in J. D. Brown & Bednar, 2006). From their 2013 study examining caregivers decision-making considerations about continuing or ceasing to provide foster care, Geiger et al. (2013) noted that roughly one-third of their 649 foster parent survey participants considered ceasing their engagement due to inadequate support and respite.

## Preventing family-of-origin breakdown

### *'Edge of care' respite for young people may prevent family breakdown*

Regular, short-term overnight care in a community-based facility was found to support both the young person and their family, preventing entry into care (Dixon et al., 2015). This U.K. scoping study, which included primary research, highlighted the advantages of early intervention, with a planned programme of respite developed to meet the needs of individuals and their families, through regular, brief stays. The respite service provided all parties with a 'breathing space' during difficult times, enabling families time and support to work through their difficulties without resorting to breakdown. The majority of clients were diverted from care.

Similar findings have been reported by others (Dixon and Beihal 2007 in Baginsky et al., 2017; Borenstein & McNamara, 2015; McGrath, 2019).

### *Wrap-around respite support for families with pre-schoolers reduces family breakdown*

A U.S. study exploring whether a 'crisis nursery' service reduced the chances of subsequent engagement with foster care services highlighted literature that supported this stance (Bruns and Bujrhard 2000, Cole and Hernandez 2011, and Cowen 1998 in Crampton & Yoon, 2016). Crampton and Yoon illustrate their point by highlighting a longitudinal study by Bruns and Bujrhard in which families who received respite care experienced significantly fewer out of home placements compared to a control group. In an evaluation of five crisis nurseries, children attending crisis nurseries prior to being placed in foster care had significantly higher chances of being reunited with their family compared to children who entered foster care without experiencing the crisis nursery service (Cole and Hernandez 2011 in Crampton & Yoon, 2016). The parenting education opportunities provided as part of the crisis nursery services were highlighted as a significant contributor: parents who participated in parenting education had a 65% lower chance of their child entering foster care. Similarly, parents who accepted a recommended case management service were 65% less likely to see their child enter foster care compared to parents who declined the case management service.

Similar findings have been reported by others (Klein et al., 2018).

# RESEARCH QUESTION 5

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## What are the attributes of government and non-government respite models of care that result in wellbeing benefits for the child and/or the parent/caregiver?

A broad range of attributes were identified in the 24 items that addressed this research question. There were four attributes identified by six or more authors, and seven attributes that were identified by five or less authors. Below, the five attributes mentioned most frequently are individually synthesised, with the most frequently identified attribute described first. The attributes mentioned less frequently are listed.

### **Non-judgemental**

The attribute most frequently identified as contributing to the wellbeing benefits of respite care was the provision of a non-judgemental service. Parents said that they appreciated being listened to and not judged by staff (Lucas & Gadda, 2018). They appreciated respite carers who are respectful – especially regarding privacy; and friendly but not patronising (McKiernan et al., 2020). Supporting these findings, other research has reported that caregivers can feel guilty and embarrassed about using respite care services (Wilkie and Barr (2008) in Whitmore, 2016).

#### *Peer support groups provide non-judgemental respite*

A review of the MFM trial reported that caregivers were reassured by the non-judgemental model of care, through which caregivers meet in consistent peer-group ‘constellations’. As peers, group members have a shared understanding of the challenges experienced in caring for ‘looked after’ children (McDermid et al., 2016). Peer support models, such as MFM, have been recommended due to the apparent benefits of informal sharing of knowledge and skills (O’Rourke et al., 2019). Luzinat et al. (2020) commented that the bond between peers in support sessions provides understanding and validation, which are not generally experienced in other situations.

#### *Respite camp participants report non-judgemental support*

The ‘non-judgemental’ attribute of camps aligns strongly with a point realised above in Research Question 2, about children feeling camps are a place where they are free to be themselves, without fear of stigma or bullying. It is the experience of feeling welcomed and accepted, in contrast to a more typical experience of feeling like a ‘misfit’ in the wider community (Analytis et al., 2020; Kelada et al., 2020). From a study of a Western Australian residential camp for children cared for by their grandparents, the grandparent caregivers highly rated the use of a ‘yarning circle’ activity. Through the yarning circle, participants told their personal stories and heard the stories of others, reinforcing the common connection of similar experiences. Dare et al. (2020) described the outcome as cathartic.

### **Guided by individual needs**

From their focus group discussions with service providers, Borenstein and McNamara (2015) reported a strongly expressed understanding that potential benefits to children from respite care can only be realised if individual circumstances were adequately taken into account, with the views of the child being sought. This was especially true for young people. This point has been reinforced by

others, in relation to young people (Dixon et al., 2015; Hill, 2016), the need to be child-centred (Baginsky et al., 2017), and in relation to the unique needs of families (Eddy et al., 2020; McGrath, 2019; Cowen and Reed 2002 in Murphy et al., 2007; Whitmore, 2016). McDermid and Baker (2016) reported from their evaluation of the MFM trial, that caregivers acknowledged and appreciated respite coordination that demonstrated flexibility to meet the needs and circumstances of individuals.

## Quality of Care

### *'Quality care' is multi-dimensional*

Above is a discussion about the necessity of meeting the needs of the individual child or young person so that they reap the benefits of respite care. In a parallel theme, for caregivers to reap the benefits of respite care, they need to have confidence in the quality of respite care that will be provided to the child or young person for whom they care. Indicators of quality of care include:

- having respite carers who are appropriately skilled in addressing the particular needs of the child, as a first step to caregiver confidence about using respite care (McGrath, 2019);
- having a caring nature (McGrath, 2019);
- being respectful (McKiernan et al., 2020);
- having good communication skills (O'Rourke et al., 2019);
- knowing the child's needs and routines (McDermid et al., 2016); and
- being friendly, trustworthy, and responsive (Lucas & Gadda, 2018)

### **Quality of care was commonly valued by caregivers who responded to a pre- and post- respite care survey in the research of Remedios et al. (2015).**

In contrast, but supporting this point, it has been reported that some caregivers recognise their need for respite, but are sufficiently concerned about the quality of respite care that they feel they would be unable to enjoy the break (MacDonald and Callery (2007) in Whitmore, 2016).

## Consistent respite carer

### *Opportunities are needed so that trusting relationships can develop over time*

Having a consistent respite caregiver was rated through one survey as being the most important aspect of respite care (Borenstein & McNamara, 2015). Consistency allows for the development of relationship (Borenstein & McNamara, 2015; Dixon et al., 2015; McDermid et al., 2016), and of trust (Edelstein et al., 2017; McGrath, 2019; Ling et al. 2015 in McKiernan et al., 2020). McKiernan reports that Ling found trust to be judged by parents over time. This suggests the importance of the gradual building of a relationship between the caregiver and child, and the respite carer. The parties need opportunities to get acquainted, as McDermid and Baker (2016) observed of the MFM trial, where caregivers and respite carers were connected through the same 'constellation' or peer support group.

Where consistency of respite carer was not practiced, caregivers sought this attribute, noting that without consistency they found themselves in what they described as "a 'Catch 22' situation", illustrated by the follow extract:

*The Ottawa and Selwyn study also highlighted that respite was often not child centred and was often provided by someone the child did not know. A carer described the 'Catch 22' situation for carers:*

*I knew I deserved a break, and it was important for my own children that we had that break. But when I got them back they were like these little broken people, just the way they looked at me, it was like the trust had gone (Ottaway and Selwyn 2016, p 39 in Baginsky et al., 2017).*

## Other attributes of respite care models that result in wellbeing benefits

Other attributes of respite care models that result in wellbeing benefits to caregivers, children, and young people include:

- ‘whole of household’ approaches to respite care are favoured by many caregivers (Analytis et al., 2020; Dixon et al., 2015; Leake et al., 2019; Luzinat et al., 2020; McDermid et al., 2016; Barr et al. 2010 in O’Rourke et al., 2019);
- age-appropriate and need-appropriate activities enhance the realisation of respite care benefits (Analytis et al., 2020; Dare et al., 2020; Dixon et al., 2015; Gillard et al., 2011; O’Rourke et al., 2019);
- respite care should be normalised and planned, rather than responding only to crises and emergencies (Borenstein & McNamara, 2015; Dixon et al., 2015; McKiernan et al., 2020; Murphy et al., 2007);
- respite care needs to be well coordinated (Luzinat et al., 2020; McDermid et al., 2016; Nielsen, 2019);
- respite care camp environments need to be aligned with the needs of attendees (Analytis et al., 2020; Luzinat et al., 2020; Remedios et al., 2015);
- wrap-around care supports the realisation of respite care benefits (Dixon et al., 2015; Lucas & Gadda, 2018);
- respite care coordination services should be highly responsive, recognising the need for urgency where necessary (McDermid et al., 2016; Corkin, Price and Gillespie 2006, and Wilkie and Barr 2008 in Whitmore, 2016);
- well-designed edge of care respite for adolescents includes frequent short-stays and is highly responsive to any need for urgency (Dixon et al., 2015; O’Rourke et al., 2019);
- residential respite care facilities are enhanced by having a broad skillset across the staff (Dixon et al., 2015; Remedios et al., 2015);
- without timely and ongoing respite support, a decision to discontinue the caregiving role may be accelerated (Murphy et al., 2007); and
- trauma-informed approaches are valued (Leake et al., 2019).

# FINDINGS

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The evidence presented in this evidence brief shows that respite care is most effective when it:

- Recognises the value of normalised, planned respite care as a preventative measure that is likely to improve stability for children and young people in its care; and
- Recognises that provision for emergency care will always be needed.

The section summarises the key findings from the evidence review that are likely to have policy or practice implications for Oranga Tamariki, and provides high-level recommendations for further investigation.

## *Planned, normalised respite care is likely to improve care stability*

There is evidence that respite care that is planned and routinised is more protective against a breakdown in care arrangements than emergency respite care alone. While there needs to be provision for emergency respite care, this alone is insufficient for the needs to caregivers. Stability of care arrangements is a tremendous benefit to children, and planned respite care supports stability.

## *School Holiday Camps*

The literature has shown the camp environment to have considerable benefits to participant wellbeing. One way to provide planned respite care is to bring children or young people together, in age- and situation-appropriate groups, through school holiday camps designed to improve socialisation, resilience, and self-esteem through the introduction of skill-building activities.

## *Mockingbird Family Model*

The literature suggests this model to be especially supportive of caregiver wellbeing as well as providing children living in care with an expanded sense of family. In areas where clusters of caregivers are located, this model could be trialled in Aotearoa New Zealand. This would potentially provide access to short breaks as well as emergency care with a family who is known to the caregiver and the child or young person, addressing the point that having a consistent respite caregiver is highly desired. The following point is not extracted directly from the literature but may nevertheless be worth consideration. In the Aotearoa New Zealand context, it would likely be appropriate to bring a cultural lens to such groups, and in so doing, help children who are living in care to develop, maintain, or strengthen their links with their culture.



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# APPENDIX 1: ATTRIBUTES OF THE LITERATURE

Citation	Year	Care Setting	Condition	Sample Size	Study type	Jurisdiction
Analytis, Penelope, Narelle Warren, and Jennie Ponsford. 'Supporting Children and Young People with an Acquired Brain Injury: A Review of the Literature'. United Kingdom: Evidence Review, 2020.	2020	Camp	Acquired brain injury	29	Primary Qualitative	Australia
Baginsky, Mary, Sarah Gorin, and Claire Sands. 'The Fostering System in England: Evidence Review'. United Kingdom: Evidence Review, 2017.	2017	Mixed	Welfare-involved	Not Applicable	Literature Review	United States
Borenstein, Juliette, and Patricia McNamara. 'Strengthening Kinship Families: Scoping the Provision of Respite Care for Children'. United States: Foundation for Child Development, 2015.	2015	Camp	Welfare-involved	18	Primary Qualitative	Australia
Dixon, Jo, Jenny Lee, Sarah Ellison, and Leslie Hicks. 'Supporting Adolescents on the Edge of Care. The Role of Short Breaks'. United States: Foundation for Child Development, 2015.	2015	Not Applicable	Welfare-involved	Not Applicable	Opinion Piece	United States
Brown, Jason D., and Lisa M. Bednar. 'Foster Parent Perceptions of Placement Breakdown'. Children and Youth Services Review, 2006.	2006	Not Applicable	Welfare-involved	63	Primary Qualitative	Canada
Contact a Family. 'Short Breaks - Help for You & Your Child to Take a Break'. Contact a Family, 2018.	2018	Not Applicable	Disabilities	Not Applicable	Not Applicable	United Kingdom
Crampton, David, and Susan Yoon. 'Crisis Nursery Services and Foster Care Prevention: An Exploratory Study'. Child Welfare, 2016.	2016	Daytime programme	Welfare-involved	186	Primary Quantitative	United States
Dare, J., R. Marquis, E. Wenden, S. Gopi, and D. A. Coall. 'The Impact of a Residential Camp on Grandchildren Raised in Residential Care'. Australia: Australian Institute of Family Studies, 2020.	2020	Camp	Welfare-involved	34	Primary Qualitative	Australia
Dixon, Jo, Jenny Lee, Sarah Ellison, and Leslie Hicks. 'Supporting Adolescents on the Edge of Care. The Role of Short Breaks'. United States: Foundation for Child Development, 2015.	2015	Mixed	Welfare-involved	50	Primary Qualitative	United Kingdom
Eddy, J. Mark, Joann Wu Shortt, Charles R. Martinez, Alice Holmes, Alice Wheeler, Jeff Gau, John Seeley, and Jean C. S. J. 'The Impact of a Residential Camp on Grandchildren Raised in Residential Care'. Australia: Australian Institute of Family Studies, 2020.	2020	Daytime programme	At risk of abuse or neglect	180	Primary Qualitative	United States
Edelstein, H., J. Schipke, S. Sheffe, and S. Kingsnorth. 'Children with Medical Complexity: A Scoping Review of International Literature'. United States: American Academy of Pediatrics, 2017.	2017	Not Applicable	Complex medical needs	Not Applicable	Literature Review	Literature Review
Flynn, Rachel M., Ashley A. Ricker, Curtis Dolezal, Mike Kunin, and Claude A. Mellins. 'Residential Summer Camp for Children with Disabilities'. United States: American Academy of Pediatrics, 2019.	2019	Camp	ADHD, autism, learning disabilities	1392	Primary Quantitative	United States
Geiger, Jennifer Mullins, Megan J. Hayes, and Cynthia A. Lietz. 'Should I Stay or Should I Go? A Mixed Methods Study of Foster Parents' Perceptions of Short Breaks'. United States: American Academy of Pediatrics, 2013.	2013	Caregivers home	Welfare-involved	649	Survey	United States
Gillard, Ann, Peter A. Witt, and Clifton E. Watts. 'Outcomes and Processes at a Camp for Youth With HIV/AIDS'. Qualitative Health Research, 2011.	2011	Camp	Life-limiting conditions	51	Primary Qualitative	United States
Gita Cugley & Associates Consulting. 'Landscape Analysis of Recruitment of Resource Families for Children Ages 0-18'. United States: Gita Cugley & Associates Consulting, 2018.	2018	Caregivers home	Welfare-involved	Not Applicable	Gap analysis	United States
Greenfields, Margaret, and June Statham. 'Support Foster Care: Developing a Short-Break Service for Children in Need'. United Kingdom: Department of Health, 2004.	2004	Caregivers home	Welfare-involved	Not Reported	Survey	England
Harper, Amber, Tina Taylor Dyches, James Harper, Susanne Olsen Roper, and Mikle South. 'Respite Care, Marital Quality, and Parenting: A Study of Foster Parents'. United States: American Academy of Pediatrics, 2013.	2013	Caregivers home	Fetal Alcohol Spectrum Disorder	101	Survey	United States
Hill, K. 'Respite Services for Children with Life-Limiting Conditions and Their Families in Ireland'. Nursing Children and Young People, 2016.	2016	Not Applicable	Life-limiting conditions	Not Applicable	Opinion Piece	Republic of Ireland
Houses of the Oireachtas. 'Report on the Provision of Foster Care Services in Ireland'. Ireland: Joint Committee on Children and Youth Affairs, 2017.	2017	Caregivers home	Welfare-involved	Unassigned	Unassigned	Republic of Ireland
Jedwab, Merav, Anusha Chatterjee, and Terry V. Shaw. 'A Review of Foster Home Policies and Regulations in the United States'. United States: American Academy of Pediatrics, 2020.	2020	Caregivers home	Welfare-involved	Not Applicable	Literature Review	United States
Kelada, Lauren, Claire Elizabeth Wakefield, Maria C. Cruz Silva, and Christina Signorelli. 'Camps for Children with Complex Medical Needs: A Review of the Literature'. United States: American Academy of Pediatrics, 2020.	2020	Camp	Cancer	Not Applicable	Literature Review	Literature Review
Klein, Sacha, Brittany Mihalec-Adkins, Stephanie Benson, and Sei-Young Lee. 'The Benefits of Early Care and Education for Children with Disabilities'. United States: American Academy of Pediatrics, 2018.	2018	Daytime programme	Welfare-involved	78	Primary Qualitative	United States
Leake, Robin, Valerie F. Wood, Marian Bussey, and Jessica Strolin-Goltzman. 'Factors Influencing Caregiver Strain in Foster Care: A Systematic Review'. United States: American Academy of Pediatrics, 2019.	2019	Caregivers home	Welfare-involved	338	Survey	United States
Little, Michael, Georgina Warner, and Vicky Baker. 'Safe Families for Children'. Programme Evaluation. England: De Montfort University, 2017.	2017	Caregivers home	Welfare-involved	91	Evaluation	England
Lucas, Sian, and Andressa Gadda. 'Ruchazie Family Centre Evaluation: Year 2 Report'. Glasgow, UK: Ruchazie Family Centre, 2018.	2018	Daytime programme	Welfare-involved	Not Applicable	Evaluation	United Kingdom
Luzinat, Katrina J., Penelope Analytis, Amelia J. Hicks, Narelle Warren, and Jennie L. Ponsford. 'The Experience of Foster Parents: A Review of the Literature'. United States: American Academy of Pediatrics, 2020.	2020	Camp	Acquired brain injury	10	Primary Qualitative	Australia
McDermid, Samantha, Claire Baker, Doug Lawson, and Lisa Holmes. 'The Evaluation of the Mockingbird Family Model: A Review of the Literature'. United States: American Academy of Pediatrics, 2016.	2016	Caregivers home	Welfare-involved	Not Applicable	Evaluation	United Kingdom
McGrath, Aisling. 'An Exploration of Parents' Experience of Accessing Respite Care for Their Child with Autism Spectrum Disorder'. United States: American Academy of Pediatrics, 2019.	2019	Mixed	Autism spectrum disorder	6	Primary Qualitative	Republic of Ireland
McKiernan, Aidan, Alan Carr, Lynsey O'Keefe, Ellen Butler, Claire Quinn, and Suzanne Guerin. 'Levels of Satisfactoriness of Social Development: A Guide for Carers He Aratohu Ma Nga Kaihiaki'. Ministry of Social Development, 2019.	2019	Not Applicable	Disabilities	Not Applicable	Not Applicable	Aotearoa/New Zealand
Mullins, Larry L., Karen Aniol, Misty L. Boyd, Melanie C. Page, and John M. Chaney. 'The Influence of Respite Care on Foster Parents: A Review of the Literature'. United States: American Academy of Pediatrics, 2002.	2002	Mixed	Disabilities	39	Primary Mixed methods	United States
Murphy, N. A., B. Christian, D. A. Caplin, and P. C. Young. 'The Health of Caregivers for Children with Disabilities: A Review of the Literature'. United States: American Academy of Pediatrics, 2007.	2007	Caregivers home	Disabilities	40	Primary Mixed methods	United States
Neville, Alyssa R., Nivatha Moothathampy, Methuna Naganathan, Elizabeth Huynh, and Fiona J. Moola. 'A Place to Call Home: A Review of the Literature'. United States: American Academy of Pediatrics, 2019.	2019	Camp	Cancer	Not Applicable	Literature Review	Canada
Nielsen. 'How Well Is Oranga Tamariki Supporting Its Caregivers? A Survey of Oranga Tamariki Caregivers'. Wellington: Oranga Tamariki, 2019.	2019	Caregivers home	Welfare-involved	1,283	Survey	Aotearoa/New Zealand
Northwest Institute for Children and Families. 'Mockingbird Family Model Project Evaluation: Year Three Evaluation Report'. United States: Northwest Institute for Children and Families, 2006.	2006	Caregivers home	Welfare-involved	22	Primary Qualitative	United States
Norton, Michelle. 'Respite Care, Stress, Uplifts, and Marital Quality in Parents of Children with Down Syndrome'. Birth Defects Research, 2016.	2016	Caregivers home	Disabilities	224	Survey	United States
Oranga Tamariki Evidence Centre. 'Caregivers Raising Children with the Orphan Benefit and the Unsupported Child Benefit: A Review of the Literature'. Aotearoa/New Zealand: Oranga Tamariki, 2019.	2019	Not Applicable	Welfare-involved	125	Survey	Aotearoa/New Zealand
O'Rourke, Conall, Karen Galway, Cherith Semple, and Joan Ballantine. 'Literature Review and Mapping of Supportive Services for Foster Parents: A Review of the Literature'. United States: American Academy of Pediatrics, 2019.	2019	Camp	Cancer	Not Applicable	Literature Review	United Kingdom
Pope, Natalie D., J. Jay Miller, and Kalea Benner. 'Cultivating Resilience in New Foster Parents through Mentoring: A Review of the Literature'. United States: American Academy of Pediatrics, 2020.	2020	Caregivers home	Welfare-involved	22	Primary Qualitative	United States
Remedios, Cheryl, Lisa Willenberg, Rachel Zordan, Andrea Murphy, Gail Hesse, and Jennifer Philip. 'A Pre-Test and Pilot Study of a Supportive Services Program for Foster Parents'. Australia: Australian Institute of Family Studies, 2015.	2015	Non-camp residential	Life-limiting conditions	58	Primary Mixed methods	Australia
Roberts, Louise. 'Meeting Children's Needs within a Family Focussed Agenda: The Case of Support Care'. Children and Youth Services Review, 2015.	2015	Caregivers home	Welfare-involved	11	Primary Qualitative	United Kingdom
Roberts, Louise. 'Using Part-Time Fostering as a Family Support Service: Advantages, Challenges and Contradictions'. United States: American Academy of Pediatrics, 2016.	2016	Caregivers home	Welfare-involved	10.00	Primary Qualitative	United Kingdom
Spruin, Elizabeth, Nicola Abbott, and Nicole Holt. 'Examining the Experiences of a Short Break Scheme amongst Adoptive Families: A Review of the Literature'. United States: American Academy of Pediatrics, 2018.	2018	Daytime programme	Disabilities	11	Primary Mixed methods	United Kingdom
The Fostering Network Wales. 'Support Care Policy and Procedures Guidelines'. The Fostering Network Wales, ND.	ND	Caregivers home	Welfare-involved	Not Applicable	Policy	Wales
The Mockingbird Society. 'Mockingbird Family Model: 2009 Management Report on Program Outcomes January 1 to December 31, 2009'. United States: Mockingbird Society, 2009.	2009	Caregivers home	Welfare-involved	200	Outcomes Report	United States
Welch, Vicki, Michelle Collins, Chris Hatton, Eric Emerson, Janet Robertson, Emma Wells, and Susanne Langer. 'Short Breaks: A Review of the Literature'. United States: American Academy of Pediatrics, 2014.	2014	Mixed	Disabilities	425.00	Primary Mixed methods	United Kingdom
White, Geoff, and Lisa McCrindle. 'Interim Evaluation of Flying Start: Final Report to the Welsh Assembly Government'. United States: American Academy of Pediatrics, 2010.	2010	Daytime programme	Welfare-involved	Not Applicable	Evaluation	United Kingdom
Whitmore, Kim E. 'Respite Care and Stress Among Caregivers of Children With Autism Spectrum Disorder: An Integrative Review'. United States: American Academy of Pediatrics, 2016.	2016	Daytime programme	Fetal Alcohol Spectrum Disorder	22	Primary Qualitative	United States
Williams, Philippa. 'Support Care: The Preventative Face of Foster Care: A Report to Disseminate the Findings of the Literature Review'. United States: American Academy of Pediatrics, ND.	ND	Caregivers home	Welfare-involved	Not Applicable	Outcomes Report	Wales

# APPENDIX 2: QUALITY ASSESSMENTS

Six of most frequently cited items in this evidence brief were critically appraised.

For five items, the DFID process was used. Four of these items were found to be high quality and one was found to be of moderate quality. See Figure 1.

For one item, the AMSTAR2 process was used, with this item found to be of moderate quality. See Figure 2.

Citation	Year	Type of research	Data Collection methods	Research design	Conceptual Framing			Transparency			Appropriateness			Cultural Sensitivity	Measurement Validity	Internal Validity	External Validity	Ecological Validity	Reliability: Stability	Reliability: Internal	Reliability: Analytical	Cogency		Overall quality rating		
					Does the study acknowledge existing research?	Does the study construct a conceptual framework?	Does the study pose a research question or test a hypothesis?	Does the study present or link to the raw data it analyses?	What is the geography/context in which the study was conducted?	Does the study declare sources of support/funding?	Does the study identify a research design/method?	Does the study demonstrate why the chosen design and method are well suited to the research question?	Does the study explicitly consider any sensitive specific cultural factors that may bias the analysis/finding?	To what extent does the study demonstrate measurement validity?	To what extent is the study internally valid?	To what extent is the study externally valid?	To what extent is the study ecologically valid?	To what extent are the measures used in the study stable?	To what extent are the measures used in the study internally reliable?	To what extent are the findings likely to be sensitive/robust/transferable depending on the analytical technique used?	Does the author 'signpost' the reader throughout?	To what extent does the author consider the study's limitations and/or alternative interpretations of the analysis?	Are the conclusions clearly based on the study's results?	High Moderate Low	↑ ↓	
McGrath, Andrew. 'An Evaluation of Parental Experience of Accessing Respite Care for Their Child with Autism Spectrum Disorder', 2014. <a href="http://dx.doi.org/10.1111/cps.12055">http://dx.doi.org/10.1111/cps.12055</a> .	2019	Primary	Qualitative	Primary: Observational (neither randomised nor controlled)	yes	yes	yes	Ireland	yes	yes	yes	yes	yes	not applicable	not applicable	appropriate	appropriate	not applicable	appropriate	somewhat	yes	appropriate	yes	↑		
Bowman, Juliette, and Patricia McManus. 'Strengthening Kinship Families: Scope for the Provision of Respite Care in Australia', Child & Family Social Work 20, no. 1, (2015): 50-61. <a href="http://dx.doi.org/10.1111/cfs.12055">http://dx.doi.org/10.1111/cfs.12055</a> .	2015	Primary	Both quant and qual	Primary: Observational (neither randomised nor controlled)	yes	no	yes	Australia	no	yes	yes	yes	yes	appropriate	not applicable	appropriate	appropriate	somewhat	appropriate	appropriate	yes	appropriate	yes	↑		
Parke, Elizabeth, Nicole Abbott, and Nicole Jack. 'Examining the Effectiveness of a Short Break Scheme amongst Adult Carers with Disabled Service Users and Their Parents', International Journal of Disability, Development and Education 65, no. 2 (4 March 2018): 148-61. <a href="https://doi.org/10.1080/10401912.2017.1346599">https://doi.org/10.1080/10401912.2017.1346599</a> .	2018	Evaluation/review	Both quant and qual	Primary: Observational (neither randomised nor controlled)	yes	no	yes	United Kingdom	no	yes	yes	yes	not apparent	appropriate	appropriate	appropriate	appropriate	appropriate	appropriate	somewhat	somewhat	appropriate	yes	→		
Anahit, Penelope, Narella Warren, and Louise Poulford. 'Supporting Children and Young People with an Acquired Brain Injury (ABI) and Their Siblings: The Experience of a Camp for Families with a Child with an ABI', Neuroergonomics and Rehabilitation 5, no. 0 (26 February 2020): 1-17. <a href="https://doi.org/10.1080/09600111.2020.1721556">https://doi.org/10.1080/09600111.2020.1721556</a> .	2020	Primary	Qualitative	Primary: Observational (neither randomised nor controlled)	yes	yes	yes	Australia	yes	yes	yes	yes	not apparent	not applicable	appropriate	appropriate	appropriate	appropriate	appropriate	appropriate	somewhat	yes	appropriate	yes	↑	
McDermid, Samantha, Claire Baker, Doug Lawson, and Lisa Holmes. 'The Evaluation of the Mockingbird Family Model': Programme Evaluation, Department of Education, UK, 2016.	2016	Evaluation/review	Both quant and qual	Primary: Observational (neither randomised nor controlled)	no	yes	yes	United Kingdom	implied	yes	yes	yes	not apparent	appropriate	appropriate	appropriate	appropriate	appropriate	appropriate	appropriate	appropriate	yes	appropriate	yes	↑	

Figure 1: Five items assessed guided by the DFID process



Kelada, Lauren, Claire Elizabeth Wakefield, Maria C. Cruz Silva, and Christina Signorelli. 'Camps for Children with Cancer and Their Families: A Systematic Review of Psychosocial and Physical Impacts'. *Journal of Developmental & Behavioral Pediatrics* 41, no. 2 (March 2020): 145–156. <https://doi.org/10.1097/DBP.0000000000000728>

AMSTAR 2 TOOL QUESTION		Answer	Comment
1	Did the research questions and inclusion criteria for the review include the components of the PICO?	Yes	
2	Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?	Yes	
3	Did the review authors explain their selection of the study designs for inclusion in the review?	Yes	
4	Did the review authors use a comprehensive literature search strategy?	Yes	
5	Did the review authors perform study selection in duplicate?	Yes	
6	Did the review authors perform data extraction in duplicate?	Yes	
7	Did the review authors provide a list of excluded studies and justify the exclusion?	No	Counts of excluded studies, and t reason for exclusion, are provide
8	Did the review authors describe the included studies in adequate detail?	Yes	
9	Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?	Yes	PRISMA used
10	Did the review authors report on the sources of funding for the studies included in the review?	Yes	
11	If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12	If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13	Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14	Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	Yes	Limitations highlighted
15	If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16	Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	

Figure 2: One item assessed using the AMSTAR 2 process, with critical questions shaded

# EVIDENCE CENTRE

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