Submission No 17

CHILD PROTECTION AND SOCIAL SERVICES SYSTEM

Organisation: Centre for Community Child Health (CCCH)

Date Received: 11 December 2020

Centre for Community Child Health

murdoch children's research institute

Committee on Children and Young People
Parliament House
Macquarie Street
SYDNEY NSW 2000

11 December 2020

To Whom it May Concern,

RE: Inquiry into the child protection and social services system

We make this submission on behalf of the Centre for Community Child Health (CCCH), which is part of the Murdoch Children's Research Institute, a department of The Royal Children's Hospital Melbourne, and an academic centre of the University of Melbourne. The CCCH is committed to achieving the best possible health, development and wellbeing outcomes for children, families and communities through an agenda that focuses on promotion and prevention. We strive for evidence-based policy, evidence-based service delivery and professional practice, and equity of health, development, and wellbeing outcomes among Australian children. For more information, please see our website: https://www.rch.org.au/ccch/.

In the context of this inquiry, we present findings from three of our unique Australian studies that work to support families experiencing adversity, including children in out-of-home care.

1. The health needs and experiences of Australian children in out-of-home care, and barriers and enablers to accessing health care; please see three published papers by McLean et al attached.
   Relevant for Terms of Reference 1, 2, and 4.

Children and young people entering out-of-home care (and those at risk of OOHC) are known to have higher health needs than others the same age, across all domains of health: physical, developmental, behavioural, and mental health (as outlined in McLean, Little, Hiscock, Scott & Goldfeld, 2019). Current National Standards for Out-of-Home Care include Standard 5, that children entering OOHC have their health needs assessed and attended to in a timely way. This requires a cross-sectoral service response and can be challenging to deliver (see McLean, Hiscock, Scott & Goldfeld 2020 and McLean, Clarke, Scott, Hiscock & Goldfeld 2020). Foster and kinship carers often experience delays in receiving necessary paperwork (e.g., Medicare numbers), difficulty navigating complex or poorly integrated health systems, challenges obtaining appropriate consent for healthcare, and inadequate publicly funded health services. While our work has focused on children who have entered OOHC (and for whom the State has assumed some responsibility), higher health needs in all children living with adversity increase demands on caregiver capacity and family functioning and therefore potentially increase the risk of CP involvement. An integrated response between health and child and family services sectors is essential to optimise outcomes.

2. **The benefits of a nurse home visiting program ("right@home") to parenting, the home learning environment, mothers' mental health and wellbeing; please see a published paper by Goldfeld et al., attached.**
   Relevant for Terms of Reference 1, 2, 3, and 8.

"right@home" is an award-winning, multidisciplinary research and capacity-building program that is embedded into Australia's universal and free Child and Family Health nursing service, and has significantly reduced the impact of social adversity on pregnant women and their subsequent children. Led by a partnership between the Centre for Community Child Health, Western Sydney University and Australian Research Alliance for Children and Youth, right@home was funded by the Victorian and Tasmanian governments and philanthropy to evaluate whether nurse home visiting could reduce childhood inequities in Australia. Parents who take part in right@home receive 25 home visits by a specially trained MCH nurse, who is further supported by a social worker. Most previous nurse home visiting programs evaluated by randomised trial (the gold standard) were designed for the US health system, and are limited to young, first-time mothers and their children. To maximise right@home's reach and social impact in countries with universal health care, we custom-built a nurse home visiting program that could increase the equitable delivery of Australia's universal Child and Family Health nursing service, for women of any age and parity. Our randomised trial of the program demonstrated that it benefited parents' care of and responsivity to their child, and the home learning environment at 2 years (Goldfeld, Price, Smith et al. 2018) and benefited women's mental health and wellbeing at 3 years (Goldfeld et al. *In press*).

3. **An overview of our work to support families who are experiencing financial hardship and deprivation, through better links between Australia's existing universal health and social care sectors ("Healthier Wealthier Families"); 2-page description attached.**
   Relevant for Terms of Reference 1, 2, and 8.

Poverty and deprivation can harm children's future health, learning, economic productivity, and societal participation. The Australian Healthier Wealthier Families project seeks to reduce the childhood inequities caused by poverty and deprivation by creating a systematic referral pathway between two free, community-based services. The universal, Child and Family Health nursing service provides health and development support to families with children from birth to school entry. Free and independent financial counselling is a major element of the current Australian policy response to poverty. These services advocate for people experiencing financial hardship and help families and young people make independent and informed choices about their money. However, many people do not seek financial help until they reach crisis. By adapting a successful Scottish model, the objectives of this Australian research are to test the feasibility of systematising the referral pathway, and short-term impacts on household finances, caregiver health, parenting, and financial service use. This project works at the health and social care interface to try and address family and child health and social inequity, by maximising the effectiveness and efficiency of current services.

Please let us know if we can help provide any more information or discussion about this research evidence for Australian children.

Yours sincerely – on behalf of the Centre for Community Child Health,

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Centre for Community Child Health

Healthier Wealthier Families

Information for Stakeholders

In Australia, at least 1 in 6 children live in poverty, and one quarter experience deprivation (such as missing out on proper nutrition, housing and supportive personal relationships) due to financial hardship.

Poverty and deprivation are more commonly experienced by women, young or one parent families, people from culturally and linguistically diverse backgrounds, and people experiencing disability and chronic disease.

Australia has a social care system that offers support to families in need. However, families can face stigma and barriers to the services and supports available. These same families may also have lower financial literacy and are at greater risk of being targeted by high-cost and harmful debt services, gambling providers, and pay-day lenders. By making better use of Australia's existing infrastructure, it is possible to reduce childhood poverty and deprivation.

Why is the issue important?

Poverty can harm children's future health, learning, economic productivity and participation in society. Without help, poverty can persist across generations. This is a major public health issue. Reducing poverty and inequity will help our whole society be healthier and wealthier.

Key messages

- Poverty in early childhood can have a lasting impact on health and development. In Australia, at least 1 in 6 children experience poverty and deprivation. By school entry, they have three times the developmental vulnerability of their advantaged peers. As adults, they experience worse health, less wealth, and shorter lives.
- The Healthier Wealthier Families (HWF) project will work at the health and social care interface to connect two freely available services: community-based nurses (known as Maternal and Child Health (MCH) or Child and Family Health (CFH) nurses) and financial counsellors.
- By taking a preventative approach against poverty and deprivation through existing services, HWF aims to improve health, social and economic outcomes for children and families.

Trial registration: ACTRN12620000154909

What is Healthier Wealthier Families?

Healthier Wealthier Families will test the feasibility and benefits of linking Australia's existing MCH/CFH nursing and financial counselling services, and to assess whether it can improve the quality, efficiency and coordination of responses to poverty and deprivation at little upfront cost.

- Free and independent financial counselling is a major element of the current Australian policy response to poverty.
- These services advocate for people experiencing financial hardship, and help families make independent and informed choices about their money. However, many parents do not seek financial help until they reach crisis.
- MCH/CFH nursing services are free and universally available. Nurses use preventative approaches to promote child and family health, and already ask about a range of sensitive issues such as postnatal depression and family violence.

In the HWF model, nurses will identify families who could benefit from preventative and early referral to a financial counsellor. The model is being pilot tested in three Australian sites: Whittlesea and Wodonga in Victoria, and Fairfield in New South Wales. It is led by a collaboration between the Centre for Community Child Health and BEST START-SW, in partnership with the Cities of Whittlesea and Wodonga Maternal and Child Health, South Western Sydney Child and Family Health, Uniting Vic.Tas, Upper Murray Family Care, Wesley Mission, the Melbourne Institute: Applied Economic & Social Research, the University of Melbourne, RMIT University, Western Sydney University, and the University of New South Wales.

The pilot study is the first step toward a large-scale trial to examine whether linking these health and social care services can improve the health and wellbeing of Australian children and families.

Has this worked anywhere else?

Healthier Wealthier Families is an adaption of a model used in Glasgow, Scotland to reduce child poverty. In 2010, the Scottish Government funded a partnership between the National Health Service, local government and the community sector, using their early years workforce to identify and refer families to community financial counsellors.

As of 2018, this partnership model has resulted in almost 16,000 referrals and over £18 million in total financial gain for families of young children.

What does HWF hope to achieve?

Healthier Wealthier Families is a collaborative and sustainable model that aims to address family and child health and social inequity, and maximise the effectiveness and efficiency of current services.

Planned milestones

January 2020: Develop partnerships and establish pilot protocol

March-July 2020: Pause due to COVID-19

From August 2020: Recruitment

January 2021 onwards: Initial follow-up assessments, preliminary findings analysed

Find out more:

Victoria: Dr Anna Price at [redacted]

NSW: A/Prof Sue Woolfenden at [redacted]

Nurse Home Visiting for Families Experiencing Adversity: A Randomized Trial

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abstract

OBJECTIVES: Nurse home visiting (NHV) may redress inequities in children's health and development evident by school entry. We tested the effectiveness of an Australian NHV program (right@home), offered to pregnant women experiencing adversity, hypothesizing improvements in (1) parent care, (2) responsivity, and (3) the home learning environment at child age 2 years.

METHODS: A randomized controlled trial of NHV delivered via universal child and family health services was conducted. Pregnant women experiencing adversity (≥2 of 10 risk factors) with sufficient English proficiency were recruited from antenatal clinics at 10 hospitals across 2 states. The intervention comprised 25 nurse visits to child age 2 years. Researchers blinded to randomization assessed 13 primary outcomes, including Home Observation of the Environment (HOME) Inventory (6 subscales) and 25 secondary outcomes.

RESULTS: Of 1427 eligible women, 722 (50.6%) were randomly assigned; 306 of 363 (84%) women in the intervention and 290 of 359 (81%) women in the control group provided 2-year data. Compared with women in the control group, those in the intervention reported more regular child bedtimes (adjusted odds ratio 1.76; 95% confidence interval [CI] 1.25 to 2.48), increased safety (adjusted mean difference [AMD] 0.22; 95% CI 0.07 to 0.37), increased warm parenting (AMD 0.09; 95% CI 0.02 to 0.16), less hostile parenting (reverse scored; AMD 0.29; 95% CI 0.16 to 0.41), increased HOME parental involvement (AMD 0.26; 95% CI 0.14 to 0.38), and increased HOME variety in experience (AMD 0.20; 95% CI 0.07 to 0.34).

CONCLUSIONS: The right@home program improved parenting and home environment determinants of children's health and development. With replicability possible at scale, it could be integrated into Australian child and family health services or trialed in countries with similar child health services.

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Drs Goldfeld, Price, Bishop, Hiscock, and Kemp conceptualized and implemented the study design and contributed to the first and subsequent drafts of the report; Dr Gold conceptualized and implemented the study design, provided health economics expertise in the trial design, conducted the cost-evaluation analysis, and contributed to the first and subsequent drafts of the report; Dr Smith implemented the study design, is the funding holder (on behalf of the

WHAT'S KNOWN ON THIS SUBJECT: Nurse home visiting programs may be used to redress inequities for children experiencing adversity. International trials demonstrate mixed results; some have led to improved outcomes for children and families in the short- and long-term but with small-to-moderate effect sizes.

WHAT THIS STUDY ADDS: The right@home nurse home visiting program improved parenting and the home learning environment for families experiencing adversity compared with existing services. It could be integrated into well-child health care in Australia or trialed in other countries with appropriate health care provision.

To cite: Goldfeld S, Price A, Smith C, et al. Nurse Home Visiting for Families Experiencing Adversity: A Randomized Trial. *Pediatrics.* 2019;143(1):e20181206

Sustained socioeconomic and psychosocial adversity during the early years of life has wide-ranging and long-lasting consequences well into adulthood, including lower educational attainment, poorer health, and lower income.[1,2] Families experiencing this adversity often encounter barriers in accessing health and support services, which contribute to poorer outcomes for their children (described as the inverse care law[3]) contributing to the persistence of developmental inequities among children in high-income countries.[4–7]

More recent economic, health, and social research reveals that efforts to redress inequities have the greatest benefits if they are delivered during early childhood (pregnancy to 8 years of age).[8–10] Given the enduring effects of the home environment on children's development,[11,12] nurse home visiting (NHV) is an increasingly popular model of service delivery to improve service access and outcomes for families experiencing adversity. It is championed by international organizations such as the United Nations Children's Fund and was a commitment of US President Barack Obama's 2014 budget, with $1.5 billion in funding over 10 years (2015–2024) to maintain and expand evidence-based home visiting services. Despite the appeal of NHV, previous studies suggest that even the most successful programs have moderate effects in the short-term and mixed benefits in the longer-term,[13] with findings not consistently replicated across contexts. For example, researchers in a recent UK evaluation of Nurse-Family Partnership (NFP) program concluded no evidence for improved primary outcomes (smoking in pregnancy, birth weight, emergency hospital attendance and admission for the child, and subsequent pregnancy)[14]; however, researchers in a Dutch evaluation reported improved smoking, breastfeeding, and child-protection outcomes.[15]

In Australia, only the Maternal Early Childhood Sustained Home-Visiting (MECSH) program[16] has been rigorously evaluated when delivered via the existing universal, nurse-led child and family health (CFH) services.[17] Compared with those who receive usual care, mothers who were offered the intervention (25 visits from pregnancy to child age 2 years) showed results consistent with those in international NHV programs at child age 2 years; mothers were more responsive to children's needs and breastfed for longer, and those who reported psychosocial distress in pregnancy also reported benefits to their children's development and experience of motherhood.[17] This small study (*N* = 208) suggested that NHV has the potential for improving children's health and developmental outcomes.

To address the needs of families living in adversity in Australia, we collaborated with the Victorian and Tasmanian state governments and philanthropic organizations to develop and evaluate the largest multisite, multistate, randomized trial of NHV to be delivered through the existing Australian universal CFH services (right@home).[18] Given the limitations in previous research regarding impact across contexts,[19,20] we conducted a thorough development process[13,21,22] to ensure that our NHV program could be effective for an appropriately targeted population within an existing health care system.[23] We paid particular attention to program design, logic, and fidelity that are often missing from published NHV research.[24]

Like other NHV programs,[13,19] including the well-known NFP program, right@home identifies a target group of women who are at risk, aims to improve outcomes for these women and their children, uses a structured schedule of visiting, and has some commonalities in the underpinning theories and evidence base.[25–27]

However, right@home differs from these programs in the following ways:

- It was designed and tested for delivery within (and not separate from) an existing system of early childhood services.[28]
- Families were recruited who were
  - identified by using a broad range of psychosocial and socioeconomic risk factors known to negatively impact children's learning and development[29–31] (rather than families being selected only on the basis of risks such as young age, parity, or single parenthood[13]); and
  - most likely to benefit from an NHV service focused on prevention (rather than focused only on the families that were the most acutely disadvantaged [eg, those with alcohol and drug abuse]).[13]
- It was delivered by a multidisciplinary team (nurses and social care practitioners) with a strong program focus on service system engagement.[18]
- Visits (limited to ∼25) with intentionally increasing space between were scheduled to build families' problem-solving, aspirational, and self-management capacity and service system engagement.

We aimed to test whether the right@home NHV program could be used to improve outcomes in domains related to parenting and the home environment that are known to predict beneficial child developmental trajectories.[13] We hypothesized that at child age 2 years and when compared with those who are offered usual care, mothers who are offered the intervention would demonstrate improved (1) care of the child (sleeping, feeding, and safety), (2) responsivity (parenting and bonding), and (3) home learning environment (language and literacy activities).

METHODS

Design and Participants

We compared a randomized controlled trial (RCT) of NHV from pregnancy to child age 2 years with the existing CFH services (usual care). This was conducted as a superiority trial with 2 parallel groups and a primary end point at child age 2 years. Researchers recruited pregnant women attending antenatal clinics at 10 public maternity hospitals across Victoria and Tasmania from April 30, 2013, to August 29, 2014.[18] We used a brief risk factor survey of 10 broad-ranging psychosocial and socioeconomic risk factors for poorer child outcomes developed and piloted for the study, which showed that 2 (17%) or more adverse risk factors identified 61% of women who reported other more sensitive risk factors (eg, alcohol and drug use and domestic violence) in the standard clinical appointment.[32] Eligible women (1) had due dates before October 1, 2014; (2) were <37 weeks' gestation; (3) had sufficient English to complete interviews; (4) had ≥2 of 10 risk factors identified at screening (Supplemental Table 4)[29,32]; and (5) had home addresses within travel boundaries specified by participating areas. Women were excluded if they (1) were enrolled in an existing Tasmanian NHV program for 15- to 19-year-olds, (2) did not comprehend the recruitment invitation (eg, intellectual disability or insufficient English), (3) had no mechanism for contact (telephone number or e-mail address), or (4) experienced a critical event (eg, termination of pregnancy, stillbirth, or child death). Participants provided informed consent before completing the home-based baseline interview.

Randomization and Masking

After the baseline interview, participants were randomly assigned to the control or intervention arm with a 1:1 allocation following a computer-generated schedule stratified by site and parity (first-time parent versus parent with children) by using permuted blocks of sizes 2, 4, or 6. The research managerial staff, participants, and intervention teams were aware of allocation. Usual care nurses were not informed which clients were in the control group. Researchers who conducted assessments were blinded to randomization, with families being asked not to disclose their group status. Statisticians excluded randomization until all 2-year data were collected to maintain blinding.

Procedures

The right@home program was structured around the core MECSH framework and training[16,17] and bolstered by 5 evidence-based strategies for content (sleep, safety, nutrition, regulation, and bonding and/or relationship) and 2 for the delivery process (video feedback and motivational interviewing strategies), which were termed focus modules.[18] We developed a logic model that was focused on the alignment of right@home content and aimed at outcomes at child age 2 years, specifically changes in parental care and the home learning environment.

Women in the intervention were offered ~25 nurse visits (60–90 minutes each; content is in the protocol[18]), which commenced antenatally and were delivered mostly by the same trained right@home nurse. The intervention also included ≥1 visit by the program social care practitioner, who supported the nurse to deliver the intervention and provided brief counseling interventions and case management for families as needed. In contrast, the usual CFH services include 6 (Tasmania) or 9 (Victoria) consultations up to child age 2 years; the first is offered in families' homes, and successive consultations occur at a local center, with some limited program flexibility depending on family need.[18]

Outcomes

Researchers conducted assessments in participants' homes at child age 2 years. Given the complex intervention,[33] we identified 13 outcomes across the 3 domains (Table 1), which were selected a priori according to program logic and content and chosen as key determinants of child outcomes (Supplemental Tables 5 and 6). Given the complex nature of the right@home intervention, a focus on a single measure of outcome was likely to understate the effect of the trial. We therefore used multiple outcomes that could be considered in the interpretation of the effectiveness of the trial.[33] We chose secondary outcomes to reflect additional potential benefits of the intervention and enable comparison with existing NHV trials.[18] This does rely on multiple outcomes, which by their nature are related, but each reflect a different aspect of the effectiveness of the intervention. Data reduction techniques, such as using factor analysis to derive a composite, although simplifying the analyses would result in a loss of interpretability around the particular aspects of the home environment that are responsive to the intervention and conversely those in which responsiveness has not been evident. Our approach also aligns with Prinsen et al,[34] who suggest using a core outcome set to assess and report in clinical trials and to choose only 1 outcome measurement instrument for each outcome (eg, construct or domain), which we have done because each of our outcomes reflect

TABLE 1 Description of Primary Outcome Measures

Item	Description
Regular meal times	Single 5-point item ("never" to "always"); study design based on the Sleep Well Be Well Regular Bedtime item[37]
Food choices	12-item measure of food choices over last 24 h rated on a 3-point scale ("not at all," "once," or "more than once") and drawn from the LSAC[38]
Regular bedtime	Single 5-point item ("never" to "always") adapted from the Sleep Well, Be Well study[37]
Regular bed routine	Single 5-point item ("never" to "always") drawn from the Sleep Well Be Well study[37]
Safety of the environment	Items used to assess 11 aspects of home safety, which are dichotomized into "safe" versus "not safe"; study design based on The Royal Children's Hospital Safety Centre and Kidsafe checklists[39,40]
Warm parenting	6-item measure used to assess parental warmth; items rated on a 5-point scale ("never and/or almost never" to "always and/or almost always") and drawn from the LSAC[38]
Hostile parenting	5-item measure used to assess parental hostility; items rated on a 10-point scale ("not at all" to "all of the time") and drawn from the LSAC[38]
Parent responsivity and the home learning environment (6 subscales)	HOME Inventory[41]; 45-item measure composed of observation only (18 items), parent report only (8 items), and observation or parent report (19 items) used to assess the quality and quantity of stimulation and support available to a child in the home environment. Items are dichotomized ("not observed or reported" versus "observed and/or reported") and summed. Continuous total scores range from 0 to 45, with higher scores indicating a better home environment. The 6 subscales scored are parental responsivity (11 items), acceptance of the child (8 items), organization of the environment (6 items), learning materials (9 items), parental involvement (6 items), and variety in experience (5 items).

a different construct. However, we recognize the relatedness of outcomes and opportunity this affords for chance positive findings. Rather than correcting for multiple testing, we present estimated effects for each of the outcomes along with their respective confidence intervals (CIs). With this presentation of all of the outcomes, we avoid "sifting the evidence."[35] By presenting the direction, magnitude, and confidence of each estimate, evidence toward a treatment benefit is more clearly evident than through the consideration of significant versus nonsignificant findings, which can be overly conservative, particularly when correction for multiple testing is undertaken.[36]

Together with participant rating and feedback measures (Supplemental Table 5), implementation and fidelity data were also extracted from the electronic records of each nurse and/or practitioner contact with families, including visit content. Costs were calculated from a government-as-payer perspective and presented in 2017 Australian dollars. Regarding intervention costs, we used nurse records of training and supervision and electronic records of practitioner contact; participants retrospectively reported other service use at 6-monthly data collection. A cost-consequences analysis, in which the difference in costs between groups is presented alongside the set of differences across multiple outcomes, was not included. We present outcomes (Table 3, Supplemental Tables 12 and 13) and costs separately.

Statistical Analyses

The sample size was calculated to detect a minimum effect size (ES) of 0.3 SDs for the responsivity subscale of the Home Observation of the Environment (HOME) Inventory (Table 1). This represents a medium, standardized ES that allows for comparison with existing NHV literature, which typically ranges from 0.2 to 0.4 SDs.[19] To detect a minimum ES of 0.3 with 80% power at the 0.05 significance level, assuming an average intraclass correlation of 0.02 across the 18 nurse clusters (and 18 corresponding clusters reflecting varying nurse staffing in the usual care arm), the total sample size required was 714 participants (n = 357 per arm), allowing for attrition of 40% by child age 2 years.[18]

Baseline characteristics of trial arms were described by using means, SDs, medians, and interquartile ranges for continuous data and proportions for categorical data. Continuous outcomes were described by using means and SDs, and binary outcomes were described with proportions, both by treatment arm. Between-group outcome comparisons were made by following intention to treat. In unadjusted regression models (linear and/or logistic regression for continuous and/or binary outcomes), we only accounted for the stratification factors used during randomization: parity and study site. In adjusted models, we additionally accounted for baseline characteristics identified a priori: child sex, child age at the 2-year assessment, family's Socio-Economic Indexes for Areas (SEIFA) score (Supplemental Table 4), maternal education, maternal age at child's birth, parity, antenatal risk count, maternal self-efficacy, and maternal mental health. Results were reported as mean differences (plus standardized ESs to convey the size of the effect relative to the variability in the sample) and odds ratios with 95% CIs. In all regression analyses, we accounted for effects of nurse clustering.

For exploratory purposes, we conducted 4 subgroup analyses specified a priori[18] to investigate whether the intervention effect was modified according to parity (first child versus second or later child), antenatal risks ($\geq$3 vs 2 antenatal

TABLE 2 Baseline Characteristics According to Follow-up Status (ie, Retained or Lost in right@home Study) at Child Age 2 Years

Baseline Characteristics (Pregnancy)	Total (*N* = 722)		Intervention (*N* = 363)		Control (*N* = 359)	
	Retained (*n* = 596)	Lost (*n* = 126)	Retained (*n* = 306)	Lost (*n* = 57)	Retained (*n* = 290)	Lost (*n* = 69)
Mother						
Age in y, mean (SD)	27.7 (6.2)	27.2 (6.2)	27.6 (6.1)	27.0 (6.2)	27.9 (6.4)	27.4 (6.2)
DASS						
Depression, mean (SD)	2.9 (3.4)	3.3 (3.7)	3.0 (3.6)	3.5 (4.0)	2.9 (3.2)	3.1 (3.5)
Anxiety, mean (SD)	3.4 (3.4)	4.1 (3.4)	3.4 (3.4)	4.5 (3.8)	3.4 (3.4)	3.8 (3.1)
Stress, mean (SD)	5.4 (4.1)	5.8 (4.2)	5.3 (4.2)	6.5 (4.7)	5.4 (4.1)	5.2 (3.6)
Depression >85th percentile score, %	15.6	22.2	16.3	24.6	14.8	20.3
Anxiety >85th percentile score, %	40.1	53.2	40.9	56.1	39.3	50.7
Stress >85th percentile score, %	19.3	20.6	18.6	28.1	20.0	14.5
Education status, %						
Did not complete high school	24.4	28.0	24.0	29.8	24.8	26.7
Completed high school, vocational training	64.5	63.6	65.1	61.7	63.9	65.0
Completed a university degree	11.1	8.4	10.9	8.5	11.3	8.3
Marital status, %						
Single, not living with partner	25.3	34.9	28.1	29.8	22.4	39.1
Married, living with partner	73.2	61.1	70.3	66.7	76.2	56.5
Separated, divorced	1.5	4.0	1.6	3.5	1.4	4.4
Currently unemployed, %	64.3	75.6	64.1	75.4	64.5	75.4
Family income from benefit or pension, %	41.3	50.0	42.5	50.9	40.0	49.3
Ever had a drug problem, %	13.5	24.8	13.1	19.3	13.9	29.4
Experienced domestic violence in past y, %	11.0	15.9	11.2	17.5	10.8	14.5
Child						
Firstborn, %	37.6	34.1	38.2	33.3	36.9	34.8
Female sex, %	50.8	42.0	55.2	48.9	46.2	36.4
Family						
SEIFA Index of Social Disadvantage quintile, %						
1 (most disadvantaged)	41.4	47.1	42.5	55.6	40.1	40.3
2	7.8	9.9	7.7	7.4	7.9	11.9
3	39.6	28.9	39.5	25.9	39.8	31.3
4	8.5	9.1	7.7	9.3	9.3	9.0
5 (least disadvantaged)	2.8	5.0	2.7	1.9	2.9	7.5
Language other than English, %	8.6	8.8	7.6	8.8	9.5	8.8

The total range is 696 to 722, the intervention range is 351 to 363, and the control range is 345 to 359 because of missing data. Percentages may not add to 100 because of rounding. DASS, Depression, Anxiety, and Stress Scale.

risk factors), maternal mental health at baseline (poor mental health [top 15% according to UK normative data] versus not [<85th percentile]),[18,42] and self-efficacy at baseline (any lack of self-efficacy versus no lack of self-efficacy) using the adjusted regression models described above with additional terms for interaction between subgroups and trial arms.

Sensitivity analyses were conducted by using Tobit regression and ordered logistic regression to confirm that estimates from linear regression were robust for measures that did not follow a normal distribution. In sensitivity analyses, we also compared analyses that were restricted to families with complete data with those including all mothers who were initially randomly assigned, using multiple imputation techniques to account for missing data. Multiple imputation models included all the primary outcomes and covariates, with most secondary outcomes also included to improve model specification as far as model capacity would allow; 70 data sets were imputed by using chained equations. Results were not substantially altered in the sensitivity or per protocol analyses[18] (Goldfeld et al; unpublished observations). Data were analyzed by using Intercooled Stata version 14.2 for Windows (Stata Corp, College Station, TX).

The right@home program was approved by these human research ethics committees: The Royal Children's Hospital (HREC 32296), Peninsula Health (HREC/13/PH/14), Ballarat Health Services (HREC/13/BHSSJOG/9), Southern Health (HREC 13084×), Northern Health in Victoria (HREC P03/13), and the University of Tasmania (HREC H0013113).

RESULTS

Of 5586 women screened between April 30, 2013, and August 29, 2014 (Fig 1), 1427 (25.5%) were eligible for right@home; most of those who were excluded had <2 risk factors. Of 1427 women, 736 completed the baseline interview and 722 (50.6%) were enrolled in the trial, reporting slightly more

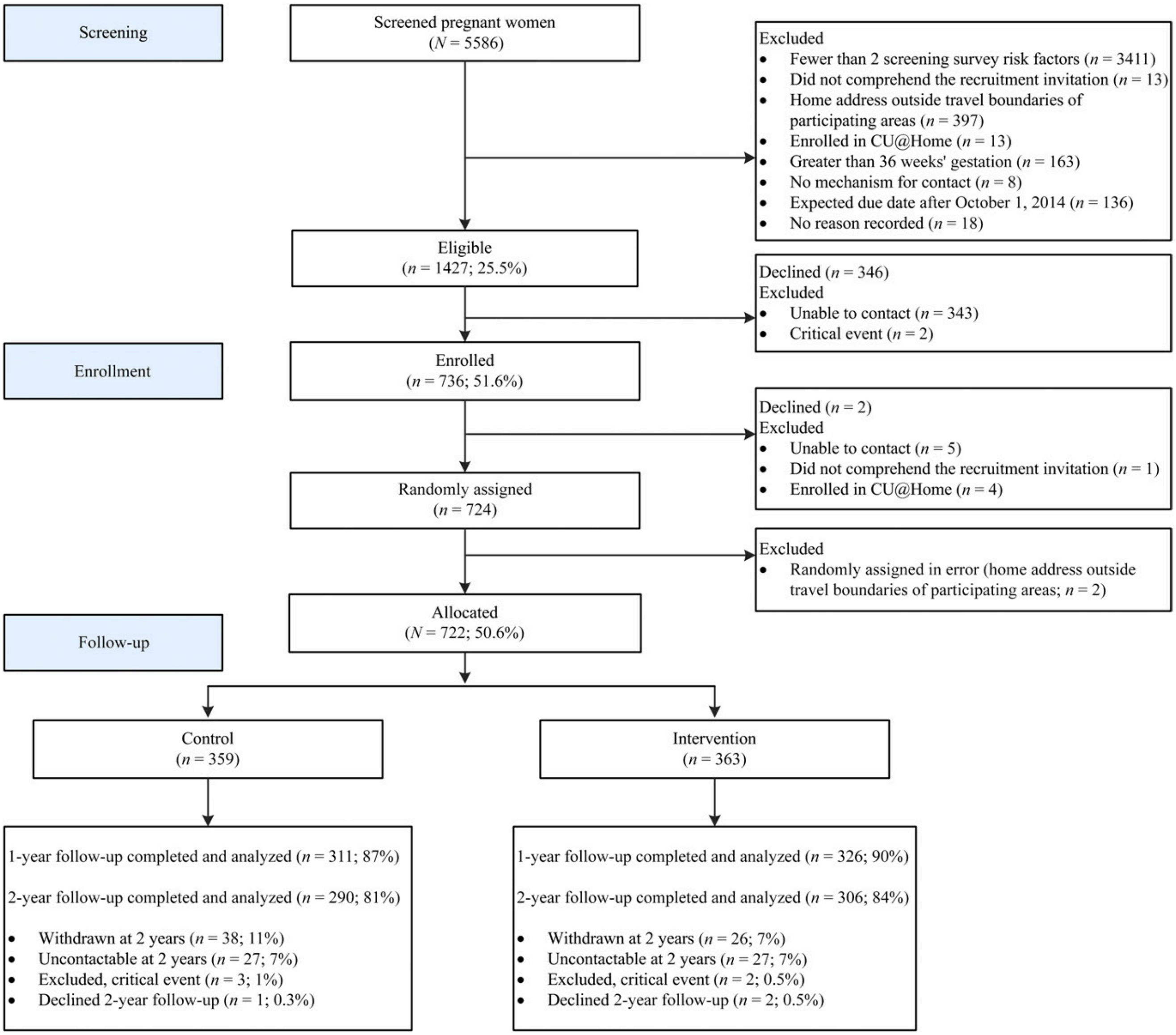

FIGURE 1
Consort diagram.

risk factors (mean = 3.2; SD = 1.3) than those who declined (mean = 3.0; SD = 1.2). Of the 722 women, 596 (82.5%) provided data at child age 2 years: 306 of 363 (84.3%) in the intervention arm and 290 of 359 (80.8%) in the control arm. Table 2 presents the selection of baseline characteristics used in the analyses; a visual inspection revealed that characteristics were similar between groups at follow-up.

The trial included women experiencing a range of adversities. Compared with mothers of infants in the nationally representative Longitudinal Study of Australian Children (LSAC),[43] women in the trial reported lower levels of tertiary qualifications (29% vs 11%), were less likely to be married or living with a partner (89% vs 73%), and more likely to live in the most socially disadvantaged areas (19% vs 41%). Women in the trial were more likely to have poor mental health compared with UK normative data,[42] and the screening risk factors presented in Supplemental Table 4 reveal high levels of antenatal risk factors of poorer global health (72%), no household income (33%), smoking (33%), and young pregnancy (27%).

Unadjusted (Supplemental Table 7) and adjusted analyses for the primary outcomes (Table 3) revealed a similar estimation of intervention effects. The intervention improved 6 of the 13 primary outcomes (small-to-moderate ESs); no effects favored the control group (Table 3, Fig 2). There was no evidence of differential effects according to whether women were at higher or lower risk for any of the 4 prespecified subgroup

TABLE 3 Results of Adjusted Regression Analyses in Which the 2 Trial Arms Are Compared on Parent Care, Responsivity, and Home Learning Primary Outcomes at Child Age 2 Years

Outcome	Descriptive Statistics				Comparative Statistic: Intervention Compared With Control				
	Intervention		Control		Adjusted				
	N	Summary[a]	*N*	Summary[a]	Statistic[b]	95% CI	*P*	ES	95% CI
Parent care									
Regular meal times[c]	298	261 (87.6)	286	255 (89.2)	0.87	0.58 to 1.31	.503	—	—
Food choices	292	10.53 (2.1)	281	10.47 (2.1)	0.01	−0.23 to 0.26	.906	0.01	−0.11 to 0.12
Regular bedtime[c]	301	261 (86.7)	286	233 (81.5)	1.76	1.25 to 2.48	.001	—	—
Regular bed routine[c]	301	251 (83.4)	286	227 (79.4)	1.39	0.94 to 2.06	.104	—	—
Safety of the environment	301	8.47 (1.17)	287	8.21 (1.32)	0.22	0.07 to 0.37	.007	0.18	0.05 to 0.30
Warm parenting	298	4.61 (0.42)	284	4.54 (0.45)	0.09	0.02 to 0.16	.012	0.20	0.05 to 0.36
Hostile parenting (reverse)	303	8.55 (1.12)	285	8.25 (1.27)	0.29	0.16 to 0.41	<.001	0.24	0.14 to 0.34
Parent responsivity and the home learning environment									
HOME parental responsivity	279	10.33 (1.18)	267	10.27 (1.13)	0.02	−0.12 to 0.17	.738	0.02	−0.10 to 0.14
HOME acceptance of the child	278	6.51 (1.26)	267	6.52 (1.27)	−0.06	−0.20 to 0.09	.446	−0.04	−0.16 to 0.07
HOME organization of the environment	294	5.44 (0.66)	283	5.33 (0.75)	0.08	−0.01 to 0.16	.079	0.11	−0.01 to 0.23
HOME learning materials	294	8.23 (1.00)	284	8.32 (1.00)	−0.08	−0.24 to 0.08	.310	−0.08	−0.24 to 0.08
HOME parental involvement	295	4.68 (1.09)	282	4.39 (1.21)	0.26	0.14 to 0.38	<.001	0.23	0.12 to 0.33
HOME variety in experience	294	3.82 (0.98)	284	3.61 (1.07)	0.20	0.07 to 0.34	.005	0.19	0.07 to 0.32

—, not applicable.

[a] Summary statistics are shown as mean (SD) except when specified as dichotomous.

[b] The comparative statistic is the mean difference for continuous outcomes (intervention minus control) and odds ratio for dichotomous outcomes (the risk of receiving the intervention compared with receiving usual care).

[c] Outcome is dichotomous (percentage).

analyses: parity, antenatal risks, maternal mental health, and self-efficacy (Supplemental Tables 8 through 11). There was evidence of positive impacts on secondary outcomes, including parenting efficacy, maternal health, and child language (Supplemental Tables 12 and 13, Supplemental Figs 3 and 4 [adjusted], Supplemental Tables 14 and 15 [unadjusted]). One secondary outcome favored the control group: child ate breakfast today (Supplemental Table 12, Supplemental Fig 3).

The 352 women in the intervention with visit data available received an average of 22.7 home visits (SD 7.4). The 301 women in the control group with CFH data available saw their CFH nurses an average of 7.6 times (SD 4.3), of which 1.4 were home visits. Per protocol guidelines,[18] 244 of 301 (81.1%) women in the control group attended at least 1 and <11 visits, and 251 of 352 (71.3%) women in the intervention received at least 75% of the 25 scheduled visits, including at least 1 antenatal visit. These proportions exclude the 11 women in the intervention and 58 women in the control group with no visit data available. The 71.3% program fidelity for the intervention arm did not meet the a priori per protocol rate of 75% of families receiving >75% of visits, including at least 1 antenatal visit, because of the high number of families (*n* = 56) that were recruited too late in pregnancy to receive an antenatal visit. Women in the intervention received an average of 1.5 more visits from social care practitioners than women in the control group (2.76 vs 1.26). Participants receiving the intervention reported more satisfaction with the intervention and more enablement to care for themselves and their children than participants receiving usual care (Supplemental Tables 12 and 13, Supplemental Figs 3 and 4 [adjusted], Supplemental Tables 14 and 15 [unadjusted]). These data were collected by blinded research assistants and compared with controls.

Combined intervention costs of CFH staff training, supervision, and visits delivered over the full program averaged $9385 per intervention participant and $1879 per control participant, an additional cost of ~$7500 that largely reflects the differential number of home visits received. There were no substantial differences in other health service use reported by participants, including allied health professionals and hospitalizations.

DISCUSSION

The right@home RCT revealed evidence of benefit across the 3 primary outcome domains of parental care, responsivity, and the home learning environment for families living in adversity. Specifically, the intervention led to more regular child bedtimes, safer home environments, warmer and less hostile parenting, improved parental involvement as a facilitator in children’s learning, and more opportunities for variety in daily

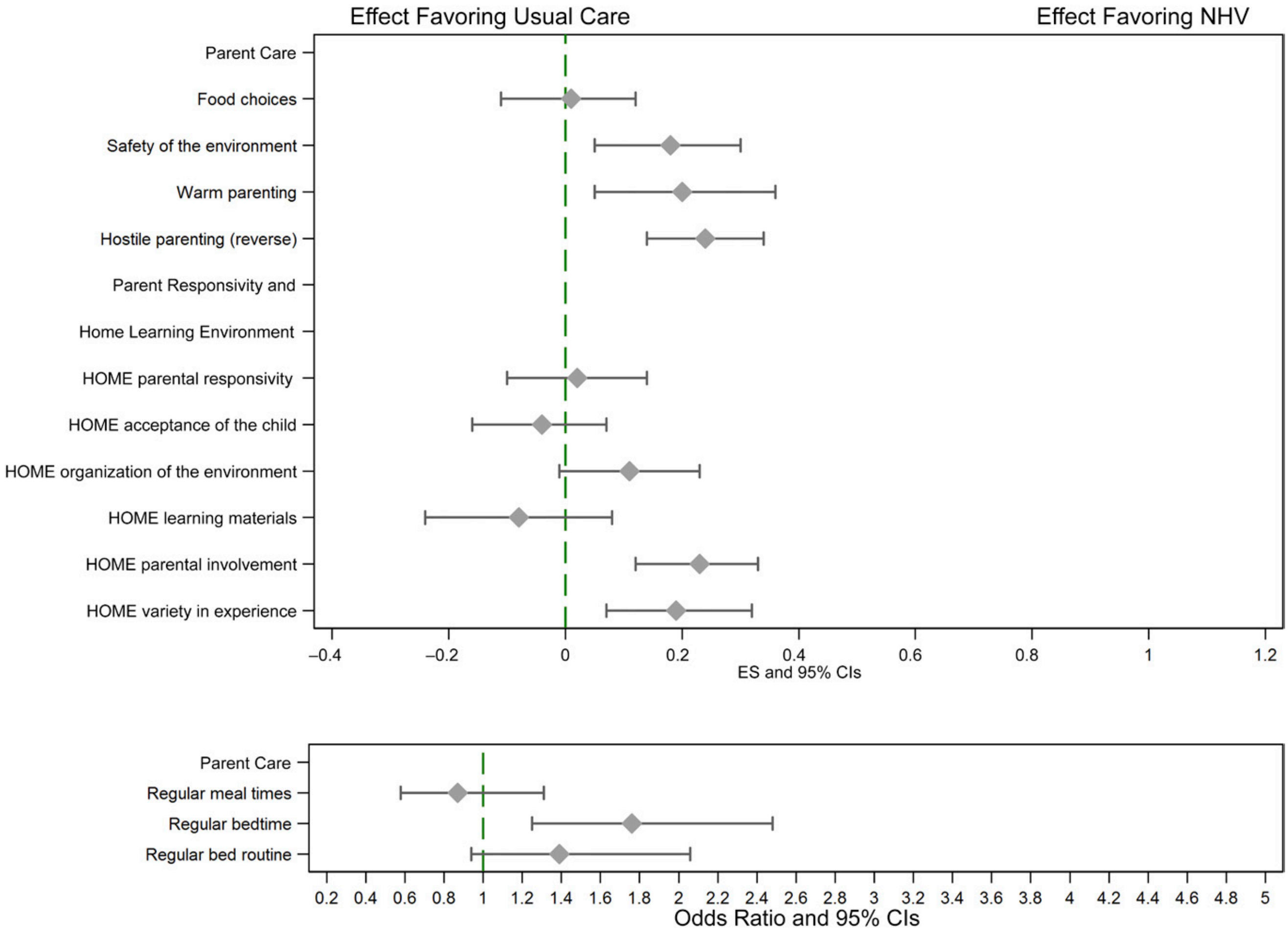

FIGURE 2

Continuous and categorical adjusted primary outcomes at child age 2 years.

stimulation and social interactions with adults other than the primary caregiver. Group differences were evident for a limited number of secondary outcomes; 6 favored the intervention group, reinforcing the primary outcomes and suggesting a broader impact of right@home (eg, parenting and maternal general health) and potential benefit for child development. The right@home program was delivered with high fidelity and retention, was well received, and significantly impacted participants' self-reported capacity to care for themselves and their children. Incremental costs were similar or less than in previous NHV interventions[14,44] but with higher retention, suggesting that the program may prove to be cost-effective in the longer-term.[44]

Within the context of NHV trials internationally, NFP (Family Nurse Partnership in the United Kingdom) has been the most frequently tested, with multiple US trials revealing improved birth, health, and child development outcomes and reductions in child maltreatment; however, findings are limited to young, first-time mothers and their children.[45] In right@home there were no differential benefits for any of these subgroups. On the US–based home visiting evidence of effectiveness Web site (https://homvee.acf.hhs.gov/), the effectiveness of NHV programs that have been tested via randomized trial according to basic criteria regarding number of impacts is reported more broadly. In comparing right@home, we found 18 other programs that managed children to 2 years of age with some similar outcome areas but variable results regarding impact. The right@home program had ESs similar to other effective NHV programs.[46] We add to the existing NHV evidence by demonstrating effectiveness when the program is (1) embedded in a population-wide system of care rather than a specialist service; (2) offered to women experiencing adversity regardless of parity, age, and antenatal risk profile; and (3) delivered with higher retention (71% receiving 75% of the program compared with, for example, 40%–52% receiving 80%[47]) and fewer visits (25 compared with, for example, 64[14]). This evidence of effectiveness through existing care systems suggests that when scaled and even with modest ESs, the program should have a public health impact at the population level.

This study had several strengths. The high retention of participants in both groups strengthens the research findings and was achieved despite the substantial adversity experienced by participants. Our findings should be generalized to pregnant women presenting to public hospitals who are experiencing high levels of adversity, a population that is often hard to recruit and retain in health care. We believe that the intervention is generalizable to similar populations (women living in adversity) in similar health care systems. This is evident locally through take up in 2 Australian states in addition to the trial and internationally through the MECSH adaptation in the United Kingdom, Korea, and the United States. In addition, our mixed-methods process evaluation (detailed in Goldfeld et al[48]) included a theory of change analysis that revealed a high correlation between nurse delivery and family expectation. Generalizability is further strengthened by the study's multisite implementation. Given the program's effectiveness across Australian states and sites, administrators start to address issues of program implementation and population generalizability. The partnership with state governments enabled the trial to be implemented at a scale that was meaningful for Australian policy makers.

An additional strength of the study is the consideration of a wide range of primary outcomes that reflect the expected benefits for families according to our program logic.[48] When considered in the context of selecting multiple primary outcomes, the consistency of effectiveness across the 3 outcome domains suggests that the findings represent genuine effects rather than isolated effects observed by chance.[33] The extensive set of secondary outcomes enables an extended evaluation of the program and comparison with outcome areas of existing home-visiting trials. This also allows for sufficient evaluation of the effectiveness of our intervention over a number of domains.[33]

There are several limitations. Because of the exclusion criteria, the findings may not generalize to non–English-speaking women or women with severe intellectual disability. If taken to scale, it would be important to consider whether the intervention should be adapted (and elements further tested) and offered in other languages and whether it would be suitable for women with intellectual disabilities. Although sensitivity analyses for missing data did not reveal changes to the results, the cessation of program delivery has the potential to introduce unmeasured bias because the reasons for cessation are unknown (ie, they could be positive, such as the family doing well and no longer requiring support, or negative, such as families being dissatisfied and refusing the service). At child age 2 years, we focused on maternal report of parenting and home learning environment outcomes per our program logic, noting these as predictors for future child outcomes.[12] Therefore, we limited our direct child observations. Although intuitively measures such as serious injuries or failure to thrive are attractive and appear to be more objective, these can be subject to ascertainment bias, particularly in this context, in which the women in 1 group are in more frequent contact with a health professional through the provision of intervention. Similarly, there is a trade-off between waiting for the children to be old enough for reliable direct developmental assessment and publishing findings. This issue has clearly vexed the researchers in other home-visit trials. For example, when we examined 11 highly-rated studies in which researchers assessed 7 models of home visiting on home visiting evidence of effectiveness, only 4 of these models included studies which assessed child behavior, development, or language using direct child assessment. Among those in which researchers used direct child assessment, only 3[49–51] included statistically significant results when using 2 measures (Bayley Scales of Infant Development used in 2 studies, Infant-Toddler Developmental Assessment used in 1 study). Parent report was otherwise used as an assessment measure. Maternal report may be subject to perception influenced by participation in the intervention. However, primary outcomes at child age 2 years were necessarily by maternal report to reflect the typical routines and interactions undertaken in caring for the children and the quality and physical safety of the home environment. Direct observation measures, such as the use of the HOME Inventory,[52] were undertaken to help mitigate the potential for bias in maternal report measures according to participation in the intervention. Direct assessments of child development will be administered at child ages 3, 4, and 5 years when these measures become feasible and reliable.[18] These include measures of learning and literacy, language proficiency, executive function and attention, social and emotional well-being, height, weight, and dental checks. Finally, researchers in previous studies have noted the differential impact of NHV on specific subpopulations, such as those with more limited psychological resources,[18] which may be important for policy makers and practitioners in terms of rationalizing service implementation. However, we were not sufficiently powered to demonstrate these differences and indeed saw no intervention effects based on our interaction analyses for the 4 subpopulations.

CONCLUSIONS

Our study findings reveal that right@home may have the potential to effect change when delivered in health care systems and targeting children and families.[53,54] The latent effects of previous NHV studies reveal that short-term outcomes can translate to substantial longer-term benefits, which in turn support the cost-effectiveness of the substantial upfront investment required for NHV.[44] Given the excellent rates of fidelity and retention, we suggest that replicability is possible at scale such that the right@home program could be integrated into well-child health care in Australia or trialed in other countries with suitable health care provision to improve outcomes for families experiencing adversity. Notwithstanding these results, to truly redress inequity for these families and their children, future researchers should investigate the potential mutual benefit of services that are both continuous and complementary over early childhood.[55] This study is a crucial contribution to the evidence that interventions can be effectively delivered within existing services to reduce the impact of social and environmental factors predisposing children to inequitable outcomes.

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ABBREVIATIONS

CFH: child and family health
ES: effect size
HOME: Home Observation of the Environment
LSAC: Longitudinal Study of Australian Children
MECSH: Maternal Early Childhood Sustained Home-Visiting
NFP: Nurse-Family Partnership
NHV: nurse home visiting
RCT: randomized controlled trial
SEIFA: Socio-Economic Indexes for Areas

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sponsor, the Australian Research Alliance for Children and Youth), and contributed to the first and subsequent drafts of the report; Dr Mensah conceptualized and implemented the study design, provided statistical expertise in the trial design and conduct of the statistical analysis, and contributed to the first and subsequent drafts of the report; Ms Orsini provided statistical expertise in the trial design, conducted the data cleaning and statistical analysis, and contributed to the first and subsequent drafts of the report; Ms Bryson implemented the study design, conducted the data cleaning and statistical analysis, coordinated and supervised data collection, and contributed to the first and subsequent drafts of the report; Ms Smith and Dr Perlen implemented the study design, coordinated and supervised data collection, and contributed to the first and subsequent drafts of the report; and all authors approved the final version of the manuscript as submitted and agree to be accountable for all aspects of the work.

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REFERENCES

1. Duncan GJ, Magnuson K. The importance of poverty early in childhood. *Policy Q*. 2013;9(2):12–17
2. Pavalko EK, Caputo J. Social inequality and health across the life course. *Am Behav Sci*. 2013;57(8):1040–1056
3. Hart JT. The inverse care law. *Lancet*. 1971;1(7696):405–412
4. Fram MS. Managing to Parent: Social Support, Social Capital, and Parenting Practices among Welfare-Participating Mothers with Young Children. Discussion Paper 1263-03. Washington, DC: Institute for Research on Poverty. 2003
5. Ghate D, Hazel N. *Parenting in Poor Environments: Stress, Support and Coping*. London, United Kingdom: Jessica Kingsley Publishers; 2002
6. Offord DR. Prevention of behavioral and emotional disorders in children. *J Child Psychol Psychiatry*. 1987;28(1):9–19
7. Watson J, White A, Taplin S, et al. *Prevention and Early Intervention Literature Review*. Sydney, Australia: New South Wales Department of Community Services; 2005
8. Kelly Y, Sacker A, Del Bono E, Francesconi M, Marmot M. What role for the home learning environment and parenting in reducing the socioeconomic gradient in child development? Findings from the Millennium Cohort Study. *Arch Dis Child*. 2011;96(9):832–837
9. Schuster MA, Fuentes-Afflick E. Caring for children by supporting parents. *N Engl J Med*. 2017;376(5):410–413
10. Caspi A, Houts RM, Belsky DW, et al. Childhood forecasting of a small segment of the population with large economic burden. *Nat Hum Behav*. 2016;1:0005
11. Foster MA, Lambert R, Abbott-Shim M, McCarty F, Franze S. A model of home learning environment and social risk factors in relation to children's emergent literacy and social outcomes. *Early Child Res Q*. 2005;20(1):13–36
12. Melhuish EC, Phan MB, Sylva K, Sammons P, Siraj-Blatchford I, Taggart B. Effects of the home learning environment and preschool center experience upon literacy and numeracy development in early primary school. *J Soc Issues*. 2008;64(1):95–114
13. McDonald M, Moore T, Goldfeld S. *Sustained Nurse Home Visiting for Families and Children: A Review of Effective Programs. Prepared for Australian Research Alliance for Children and Youth*. Parkville, Australia: The Royal Children's Hospital Centre for Community Child Health, Murdoch Children's Research Institute; 2012
14. Robling M, Bekkers M-J, Bell K, et al. Effectiveness of a nurse-led intensive home-visitation programme for first-time teenage mothers (Building Blocks): a pragmatic randomised controlled trial. *Lancet*. 2016;387(10014):146–155
15. Mejdoubi J, van den Heijkant SC, van Leerdam FJ, Heymans MW, Hirasing RA, Crijnen AA. Effect of nurse home visits vs. usual care on reducing intimate partner violence in young high-risk pregnant women: a randomized controlled trial. *PLoS One*. 2013;8(10):e78185
16. Kemp L, Harris E, McMahon C, et al. Miller Early Childhood Sustained Home-visiting (MECSH) trial: design, method and sample description. *BMC Public Health*. 2008;8:424
17. Kemp L, Harris E, McMahon C, et al. Child and family outcomes of a long-term nurse home visitation programme: a randomised controlled trial. *Arch Dis Child*. 2011;96(6):533–540
18. Goldfeld S, Price A, Bryson H, et al. 'right@home': a randomised controlled trial of sustained nurse home visiting from pregnancy to child age 2 years, versus usual care, to improve parent care, parent responsivity and the home learning environment at 2 years. *BMJ Open*. 2017;7(3):e013307
19. US Department of Health and Human Services. Home visiting evidence of effectiveness. Available at: http://homvee.acf.hhs.gov. Accessed November 4, 2015
20. Olds D. Building evidence to improve maternal and child health. *Lancet*. 2016;387(10014):105–107
21. McDonald M, Moore T, Goldfeld S. *Sustained Nurse Home Visiting for Families and Children: A Review of Effective Processes and Strategies. Prepared for Australian Research Alliance for Children and Youth*. Parkville, Australia: The Royal Children's Hospital Centre for Community Child Health, Murdoch Children's Research Institute; 2012
22. Moore T, McDonald M, Sanjeevan S. *Evidence-Based Service Modules for a Sustained Nurse Home Visiting Program: A Literature Review. Prepared for the Australian Research Alliance for Children and Youth*. Parkville, Australia: Centre for Community Child Health, Murdoch Children's Research institute; 2012
23. Marmot M, Allen J, Goldblatt P, et al. *The Marmot Review: Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010. Global Health Equity Group, Department of Epidemiology and Public Health*. London, UK: University College London; 2010
24. Filene JH, Kaminski JW, Valle LA, Cachat P. Components associated with home visiting program outcomes: a meta-analysis. *Pediatrics*. 2013;132(suppl 2):S100–S109
25. Olds DL, Eckenrode J, Henderson CRJ Jr, et al. Long-term effects of home visitation on maternal life course and child abuse and neglect. Fifteen-year follow-up of a randomized trial. *JAMA*. 1997;278(8):637–643
26. Olds DL, Henderson CRJ, Cole R, et al. Long-term effects of nurse home visitation on children's criminal and antisocial behaviour: 15-year follow-up of a randomized controlled trial. *JAMA*. 1998;280(14):1238–1244
27. Olds DL, Kitzman H, Cole R, et al. Effects of nurse home-visiting on maternal life course and child development: age 6 follow-up results of a randomized trial. *Pediatrics*. 2004;114(6):1550–1559
28. Daro D. *Embedding Home Visitation Programs Within a System of Early Childhood Services. Chapin Hall Issue*

Brief. Chicago, IL: The University of Chicago; 2009

29. Goldfeld S, D'Abaco E, Bryson H, Mensah F, Price AM. Surveying social adversity in pregnancy: the antenatal risk burden experienced by Australian women. *J Paediatr Child Health*. 2018;54(7):754–760
30. Goldfeld S, O'Connor M, Chong S, et al. The impact of multidimensional disadvantage over childhood on developmental outcomes in Australia [published online ahead of print May 29, 2018]. *Int J Epidemiol*. doi:10.1093/ije/dyy087
31. Goldfeld S, O'Connor M, Cloney D, et al. Understanding child disadvantage from a social determinants perspective. *J Epidemiol Community Health*. 2018;72(3):223–229
32. Price AM, Bryson HE, Mensah F, Kemp L, Bishop L, Goldfeld S. The feasibility and acceptability of a population-level antenatal risk factor survey: cross-sectional pilot study. *J Paediatr Child Health*. 2017;53(6):572–577
33. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M; Medical Research Council Guidance. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008;337:a1655
34. Prinsen CAC, Vohra S Sr, Rose MR, et al. How to select outcome measurement instruments for outcomes included in a "Core Outcome Set" - a practical guideline. *Trials*. 2016;17(1):449
35. Sterne JAC, Smith GD. Sifting the evidence-what's wrong with significance tests? *Phys Ther*. 2001;81(8):1464–1469
36. Perneger TV. What's wrong with Bonferroni adjustments. *BMJ*. 1998;316(7139):1236–1238
37. Quach J, Gold L, Arnup S, Sia KL, Wake M, Hiscock H. Sleep well–be well study: improving school transition by improving child sleep: a translational randomised trial. *BMJ Open*. 2013;3(10):e004009
38. Zubrick SR, Lucas N, Westrupp EM, et al. *Parenting Measures in the Longitudinal Study of Australian Children: Construct Validity and Measurement Quality, Waves 1 to 4*. Canberra, Australia: Department of Social Services; 2014
39. Kidsafe Child Accident Prevention Foundation of Australia. Home safety checklist
40. The Royal Children's Hospital. Home safety checklist: Safety Centre. Available at: www.rch.org.au/uploadedFiles/Main/Content/safetycentre/120544%20Home%20Safety%20Checklist%20A4.pdf. Accessed May 11, 2016
41. Caldwell BM, Bradley RH. *Home Observation for Measurement of the Environment: Administration Manual*. Tempe, AZ: Family and Human Dynamics Research Institute, Arizona State University; 2003
42. Henry JD, Crawford JR. The short-form version of the Depression Anxiety Stress Scales (DASS-21): construct validity and normative data in a large non-clinical sample. *Br J Clin Psychol*. 2005;44(pt 2):227–239
43. Australian Institute of Family Studies. Annual statistical reports. 2011. Available at: https://data.growingupinaustralia.gov.au/pubs/asr/2010/asr2010.pdf. Accessed July 19, 2018
44. Stamuli E, Richardson G, Duffy S, Robling M, Hood K. Systematic review of the economic evidence on home visitation programmes for vulnerable pregnant women. *Br Med Bull*. 2015;115(1):19–44
45. Avellar SA, Supplee LH. Effectiveness of home visiting in improving child health and reducing child maltreatment. *Pediatrics*. 2013;132(suppl 2):S90–S99
46. Sama-Miller E, Akers L, Mraz-Esposito A, et al. *Home Visiting Evidence of Effectiveness Review (HomVEE): Executive Summary*. Washington, DC: US Administration for Children and Families, Office of Planning, Research, and Evaluation; 2016
47. Daro D, Boller K, Hart B. *Implementation Fidelity in Early Childhood Home Visiting: Successes Meeting Staffing Standards, Challenges Hitting Dosage and Duration Targets. Mathematica Policy Research*. Chicago, IL: The University of Chicago; 2014
48. Goldfeld S, Price A, Kemp L. Designing, testing, and implementing a sustainable nurse home visiting program: right@home. *Ann N Y Acad Sci*. 2018;1419(1):141–159
49. Lowell DI, Carter AS, Godoy L, Paulicin B, Briggs-Gowan MJ. A randomized controlled trial of Child FIRST: a comprehensive home-based intervention translating research into early childhood practice. *Child Dev*. 2011;82(1):193–208
50. Olds DL, Robinson J, O'Brien R, et al. Home visiting by paraprofessionals and by nurses: a randomized, controlled trial. *Pediatrics*. 2002;110(3):486–496
51. Caldera D, Burrell L, Rodriguez K, Crowne SS, Rohde C, Duggan A. Impact of a statewide home visiting program on parenting and on child health and development. *Child Abuse Negl*. 2007;31(8):829–852
52. Caldwell B, Bradley R. *Home Observation for Measurement of the Environment: Administration Manual*. Tempe, AZ: Family and Human Dynamics Research Institute, Arizona State University; 2003
53. McLean K, Goldfeld S, Molloy C, et al. *Screening and Surveillance in Early Childhood Health: Rapid Review of Evidence for Effectiveness and Efficiency of Models*. Ultimo, NSW, Australia: The Sax Institute; 2014
54. Kuo AA, Inkelas M, Lotstein DS, Samson KM, Schor EL, Halfon N. Rethinking well-child care in the United States: an international comparison. *Pediatrics*. 2006;118(4):1692–1702
55. Heckman JJ, Mosso S. The economics of human development and social mobility. *Annu Rev Econ*. 2014;6(1):689–733

Nurse Home Visiting for Families Experiencing Adversity: A Randomized Trial

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ORIGINAL ARTICLE

Foster and kinship carer survey: Accessing health services for children in out-of-home care

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Aim: To explore the experiences of Victorian foster and kinship carers in accessing health services for children in their care and to quantify the frequency of potential barriers to health care.

Methods: On-line survey co-designed with the Foster Care Association of Victoria measuring carer-reported health service engagement by a child/young person in their care, ease of service access, time to receiving Medicare number and out-of-pocket health-related costs. A total of 239 foster and 51 kinship carers were recruited through email and social media by carer support agencies.

Results: In total, 90% of children/young people had engaged with a general practitioner. Most had engaged with dental (75%), paediatric (72%), optometry (61%) and audiology (54%) services. Mental health services were most likely to be needed but not yet received. Neither carer education nor socio-economic status was associated with likelihood of service engagement. Carers reported that it was hardest to get appointments with mental health and paediatric services.

Twenty-seven percent had waited to see a health service because of delays in carers receiving their Medicare number. Sixty percent of carers had paid out-of-pocket for health services; 78% of these had not been reimbursed.

Conclusion: Victorian foster and kinship carers report high health service use for children and young people in their care. Mental health services were the hardest to access with the largest gap between identified need and service use. Timely access to Medicare numbers and financial support are barriers to access that could be addressed. The development of integrated paediatric health care and clinicians co-located with child protection could also assist.

Key words: foster home care; health services accessibility; health services need and demand; survey and questionnaire.

What is already known on this topic

1. Children and young people in out-of-home care have higher health needs than the general population.
2. There are barriers to the provision of appropriate health care to children and young people in out-of-home care.
3. Carers play a key role in facilitating health care for these children and young people.

What this paper adds

1. This is the first Australian study exploring carer experiences accessing health care.
2. Mental health services were the hardest for carers to access, with the largest gap between need and service engagement.
3. Specific barriers to accessing health care (Medicare numbers and out-of-pocket costs) have been quantified for the first time.

On any given day in Victoria, around 8500 children and young people (aged 0–17 years) are living in a statutory out-of-home care (OOHC) placement, court ordered due to substantiated reports of abuse and/or neglect. The vast majority (94%) are in home-based placements, with either a kinship (member of the extended family or network) (73%) or foster carer (19%). More children enter and exit OOHC in Victoria, with a shorter median duration in OOHC, than any other Australian state or territory.[1]

Studies within Australia and internationally have demonstrated that these children and young people have higher prevalence of health needs across all domains of health: physical, developmental and mental health.[2–4] Due to these high rates of need, Australian and international peak health bodies and state and federal guidelines recommend routine assessment of health needs upon entry to OOHC (including dental, hearing and vision assessments), followed by the appropriate services or treatments as required.[5–7] However, in Victoria there is no state-wide pathway for the delivery of such assessments, no state-wide consistency in access to paediatricians and no monitoring of compliance with recommendations.

Access to health services for children and young people in OOHC is often complex. Barriers include insufficient availability of services,[8,9] lack of clarity around roles, responsibilities and authorisation of the adults and agencies involved,[10] bureaucratic delays and the challenges of navigating a

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[Correction added on 8th October 2020, after first online publication: Some values were corrected accordingly.]

Table 1 Survey topics and question types

Area	Topics	Question types
Carer experience	Type of carer; duration as a carer; number of children cared for; longest placement	Closed-ended
Experiences relating to a specific child/young person in their care (currently or most recently in their care)	Age bracket of child; number of previous placements; health services attended Ease of making appointments with health services	Closed-ended Likert scale
Potential barriers to health care	Medicare card/number availability Out-of-pocket expenses and frequency of reimbursement	Closed-ended
Carer impression of health needs management	Carer opinion on whether child or young person had received a comprehensive assessment of needs across different health domains	Likert scale
Demographics of respondent	Age, sex, postcode, level of education	Close-ended

Table 2 Demographics of carers and of children/young people in their care

	Foster, *n* (%)	Kinship, *n* (%)	Victorian data, %	Total, *n* (%)
Carer type	239 (82)	51 (18)	81 kinship[1]	290 (100)
Gender			Not available. Two-thirds of foster carers care with a partner[18]	
Female	190 (84)	46 (98)		236 (87)
Male	33 (15)	1 (2)		34 (13)
Prefer not to say	2 (1)	0		2 (1)
Age, years			Victorian foster carers[18]	*n* = 272†
18–35	19 (8)	7 (15)	11	26 (10)
36–45	66 (29)	9 (19)	27	127 (47)
46–65	125 (56)	26 (55)	53	99 (36)
Over 65	12 (5)	5 (11)	10	17 (6)
Prefer not to say	3 (1)	0		3 (1)
Indigenous status of carer			Victorian foster carers	*n* = 268†
Aboriginal and/or Torres Strait Islander	8 (4)	4 (9)	2.5[18]	12 (5)
Highest level of education of carer				*n* = 268†
Did not finish high school	22 (10)	7 (15)	NA	29 (11)
Year 12 or certificate III/IV	47 (21)	23 (50)	NA	70 (26)
University	153 (69)	16 (35)	43[18]	169 (63)
Length of time as carer, year			Victorian foster carers[18]	*n* = 289†
<1	27 (11)	7 (14)	15	34 (12)
1–5	101 (42)	27 (53)	41	128 (44)
6–10	42 (18)	8 (16)	18	50 (17)
>10	68 (29)	9 (18)	26	77 (27)
Age of child for health questions			Victorian data[1]	*n* = 290†
<12 months	18 (8)	1 (2)	4	19 (7)
1–3 years	42 (18)	9 (18)	1–4 years: 24%	51 (18)
4–6 years	42 (18)	14 (28)	5–9 years: 28%	56 (19)
7–12 years	86 (36)	17 (33)	10–14 years: 28%	103 (36)
13–17 years	51 (21)	10 (20)	15–17 years: 16%	61 (21)
Indigenous status of child				
Aboriginal and/or Torres Strait Islander	61 (26)	10 (20)	26[1]	72 (25)
Number of previous placements of child			NA	*n* = 290†
0	43 (18)	23 (45)		66 (23)
1	48 (20)	16 (31)		64 (22)
2	26 (11)	1 (2)		27 (9)
3 or more	101 (42)	10 (20)		111 (38)
Do not know	21 (9)	1 (2)		22 (8)

†Questions were not mandatory, therefore total (*n*) varies.

Percentage totals may exceed 100 due to rounding.

NA: Not available.

complicated health system.[10,11] The foster or kinship carer plays an important role in facilitating health care but also faces the logistic difficulties inherent in attending appointments including time, parking, child-care for other children in their care and out-of-pocket costs.[8,11,12]

There are several studies that explore the experience of kinship and foster carers in accessing health services for children in their care, some of which focus specifically on access to mental health services. International studies have identified challenges with inadequate service provision across paediatric and mental health services, long waiting lists and out-of-pocket costs to carers.[8,9]

We have only identified a handful of papers exploring the experiences of carers in Australia. Octoman and McLean[13] surveyed carers (predominantly in South Australia, New South Wales and Queensland) and found they wanted better access to general practitioners (GPs) and mental health services to respond to mental health and behavioural needs. Sawyer *et al.*[14] also found the carers reported difficulty accessing mental health services in a timely way, with only half of young people identified as needing help receiving it in the previous 6 months. A qualitative study of carers in Queensland found they reported difficulties accessing resources, including counselling.[15] To our knowledge, there have been no studies either quantifying or exploring carer experiences within Victoria. Since child protection services and many health services are delivered by state governments within Australia, it is important to understand the issues in each different system.

We therefore aimed to identify some experiences of Victorian foster and kinship carers in accessing health services for children in their care and to quantify the frequency of two potential barriers to health care.

Methods

Survey design

We co-designed an online survey (refer Appendix S1 for full survey) with the Foster Care Association of Victoria to ask carers about their experiences. The topics for inclusion in the survey arose from the Foster Carer Handbook Victoria[16] and previous literature review (see Table 1). The wording of both questions and answers was refined based on feedback from pilot participants.

Participants

The target population was foster and kinship carers in Victoria, who had cared for a child or young person on statutory child protection orders within the last 5 years, with only one survey to be completed per household.

Recruitment occurred through peak carer bodies and foster and kinship care agencies. The public survey link was distributed via email, hard-copy newsletter and through social media channels by the FCAV. The link was also promoted by Kinship Carers Victoria and some Victorian community service organisations who support foster and/or kinship carers, with reminders during the 10 weeks that the survey was open (September–December 2018).

Data collection and analysis

Study data were collected and managed using REDCap (Research Electronic Data Capture; Vanderbilt University, Nashville, Tennessee, USA), a secure, web-based data capture application hosted at the Murdoch Children's Research Institute.[17]

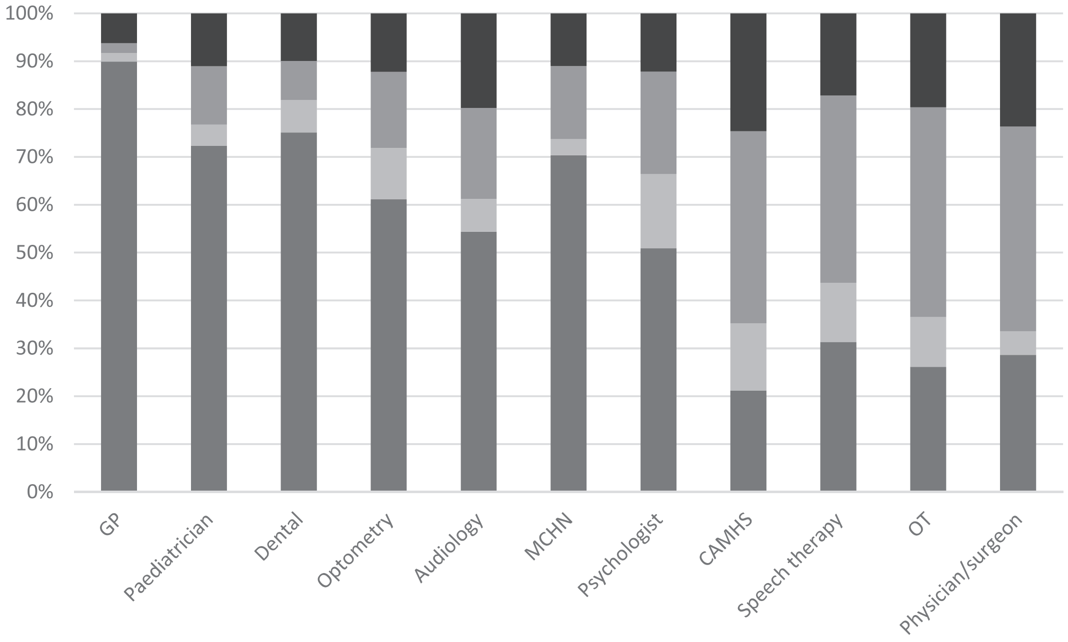

Fig 1 Proportion of children/young people engaged with health services. CAMHS, Child and Adolescent Mental Health Service; GP, general practitioner; MCHN, Maternal and Child Health Nurse. (■), Engaged with service; (□), needs service; (▨), does not need service; (■) do not know.

Table 3 Proportions engaging with health services and risk ratios

	General practitioner		Paediatrician		Dentist		Audiology		Optometry		Psychology		CAMHS	
	% engaged	Risk ratio (95% CI)	% engaged	Risk ratio (95% CI)	% engaged	Risk ratio (95% CI)	% engaged	Risk ratio (95% CI)	% engaged	Risk ratio (95% CI)	% engaged	Risk ratio (95% CI)	% engaged	Risk ratio (95% CI)
Care type														
Foster	89	1.00	73	1.00	72	1.00	55	1.00	60	1.00	50	1.00	20	1.00
Kinship	92	1.03 (0.94–1.12)	71	0.98 (0.80–1.20)	90.	1.25 (1.11–1.42)**	52	0.95 (0.70–1.29)	68	1.14 (0.91–1.43)	57	1.15 (0.87–1.52)	26	1.26 (0.72–2.19)
Location														
Regional	95	1.00	81	1.00	83	1.00	60	1.00	69	1.00	50	1.00	22	1.00
Metropolitan	89	0.94 (0.87–1.01)	68	0.84 (0.72–0.98)*	70	0.84 (0.74–0.97)*	54	0.90 (0.72–1.13)	56	0.81 (0.67–0.99)*	51	1.00 (0.78–1.29)	22	1.01 (0.62–1.64)
SEIFA quintile														
1	86	1.00	70	1.00	75	1.00	50	1.00	57	1.00	41	1.00	19	1.00
2	94	1.10 (0.93–1.29)	83	1.18 (0.89–1.56)	84	1.13 (0.88–1.44)	63	1.27 (0.80–2.01)	67	1.17 (0.79–1.72)	55	1.32 (0.79–2.20)	23	1.26 (0.48–3.29)
3	90	1.05 (0.89–1.24)	70	1.00 (0.75–1.33)	76	1.02 (0.79–1.30)	51	1.01 (0.64–1.61)	65	1.14 (0.80–1.64)	49	1.19 (0.73–1.95)	19	1.04 (0.41–2.60)
4	92	1.08 (0.91–1.27)	72	1.02 (0.76–1.36)	74	0.98 (0.76–1.27)	56	1.11 (0.70–1.76)	63	1.09 (0.75–1.59)	54	1.30 (0.80–2.12)	25	1.35 (0.55–3.31)
5	91	1.06 (0.89–1.27)	65	0.93 (0.67–1.28)	69	0.92 (0.69–1.23)	59	1.18 (0.74–1.89)	51	0.90 (0.58–1.38)	54	1.29 (0.77–2.16)	26	1.41 (0.55–3.62)
Age of child														
<12 months	89	1.00	83	1.00	7	0.09 (0.01–0.62)*	60	1.00	14	0.25 (0.07–0.93)*	17	1.00	0	-
1–3 years	96	1.08 (0.91–1.28)	87	1.04 (0.82–1.32)	58	0.76 (0.57–1.00)	60	0.99 (0.62–1.60)	39	0.69 (0.45–1.07)	17	1.04 (0.31–3.50)	9	1.11 (0.29–4.18)
4–6 years	88	0.98 (0.81–1.19)	68	0.81 (0.62–1.07)	77	1.00	54	0.90 (0.55–1.45)	56	1.00	40	2.38 (0.80–7.04)	8	1.00
7–12 years	87	0.98 (0.82–1.17)	74	0.88 (0.70–1.12)	85	1.10 (0.93–1.30)	56	0.94 (0.60–1.47)	72	1.28 (0.98–1.67)	65	3.92 (1.38–11.1)*	25	3.15 (1.15–8.62)*
13–17 years	92	1.03 (0.86–1.23)	59	0.71 (0.52–0.96)*	87	1.13 (0.95–1.34)	45	0.75 (0.45–1.25)	76	1.35 (1.02–1.77)*	75	4.47 (1.58–12.7)**	44	5.59 (2.09–14.9)**
Education level carer														
Year 11 or below	96	1.00	79	1.00	75	1.00	57	1.00	74	1.00	50	1.00	23	1.00
Year 12 or Cert III/IV	94	0.98 (0.89–1.07)	78	0.99 (0.77–1.26)	87	1.16 (0.92–1.46)	63	1.12 (0.75–1.67)	74	1 (0.76–1.32)	48	0.96 (0.60–1.53)	24	1.05 (0.44–2.54)
University	89	0.92 (0.84–1.01)	69	0.87 (0.69–1.10)	71	0.95 (0.75–1.20)	52	0.92 (0.62–1.36)	54	0.74 (0.56–0.98)*	53	1.06 (0.69–1.62)	22	0.96 (0.42–2.18)

*$P < 0.05$, **$P < 0.01$. CAMHS, Child & Adolescent Mental Health Service; CI, confidence interval; SEIFA, Socio-Economic Indexes for Areas.

Analysis was completed using Stata version 15.1 (StataCorp, College Station, Texas, USA), including simple descriptive statistics and binomial regression analysis to explore whether: (i) engagement with health services; (ii) ease of making appointments; (iii) timely receipt of Medicare numbers or (iv) likelihood of out-of-pocket costs was associated with carer or child factors, including age of child, number of previous placements, location, carer education level or carer socio-economic status (as defined by the Socio-Economic Indexes for Areas by postcode).

This project had ethics approval from the local Human Research Ethics Committee (38163A).

Results

A total of 353 records were created in Research Electronic Data Capture, with 290 included for analysis after excluding participants who provided no answers beyond the consent page,[18] provided a postcode not within 20 km of the Victorian state border,[11] were caring for a child not on statutory orders,[3] provided no health service use data[17] and were identified as duplicates.[3]

The response rate was estimated due to the distribution method. As of 30 June 2018, children/young people were placed in 5567 Victorian carer households, including 998 foster households and 3705 kinship households although other sources suggest that there were around 1800 active foster carer households in 2018.[1,19] Our survey therefore was completed by 5.2% of all Victorian carer households, and the 239 foster carers comprise 13–24% of foster carer households.

Kinship carers were under-represented in the study. Other variables, including age and experience as a carer, were broadly consistent with the population of Victorian foster carers (Table 2).[19,20] Carers completing the survey were from across the state with 170 unique postcodes and all 17 Department of Health and Human Services areas represented amongst the 271 carers who provided their postcode. Forty-one percent did not live in metropolitan Melbourne. Carers were supported by 24 different foster carer agencies. The children/young people placed with the carers were broadly representative of the wide population living in OOHC.[1]

Carer responses for health service use were collapsed to define engagement with a service as having attended, having an appointment or being on a waiting list with a health service (the latter two categories having comparatively few responses). Carers reported over 95% of children/young people had engaged with at least one service (Fig. 1). Some carers reported they did not know about health service use; this varied by health service and most likely reflects the short-term nature of some placements. Ninety percent were known by carers to have engaged with a GP; the majority had also engaged with dental, optometry, paediatric and audiology services. Mental health services were the most likely to be needed (in the opinion of the carer) but not received (14% of children/young people). Older children were more likely to have engaged with dental, optometry and mental health services and less likely to have engaged with a paediatrician (Table 3). Compared with children living in rural areas, children living in metropolitan areas were less likely to have engaged with a paediatrician (RR 0.84, 95% confidence interval (CI) 0.72–0.98), dentist (RR 0.84, 95% CI 0.74–0.97) and optometrist (RR 0.81, 95% CI 0.60–0.78). Children living in kinship care were more likely to have engaged with a dentist (RR 1.25, 95% CI 1.11–1.42) than children living in foster care. Carer education level and carer socio-economic status were not associated with likelihood of service engagement.

Eighty-five percent of carers found it easy to get a GP appointment (Fig. 2). Despite paediatricians being the third most frequently used health service, almost half of carers (46%) reported that it was difficult to make an appointment. Mental health services were the most difficult to access, with 58% of carers who had tried to make an appointment with a psychologist and 66% who had tried with Child and Adolescent Mental Health Services reporting it was difficult. Kinship carers found it easier to get mental health appointments than foster carers (RR 1.8 (1.1–2.9) for psychology appointments, RR 2.6 (1.3–5.2) for CAMHS appointments). Location, carer education level and socio-economic status had no impact upon the ease of making appointments.

Carers were asked whether they thought the child/young person had had a good assessment of their needs across health

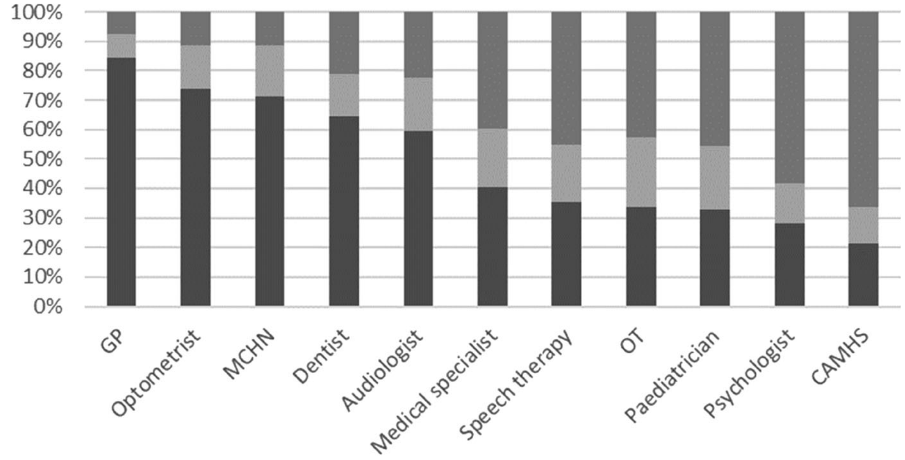

Fig 2 Ease of making appointments at health services. GP, general practitioner. MCHN, Maternal & Child Health Nurse. OT, Occupational therapist. CAMHS, Child & Adolescent Mental Health Service (■), Easy; (■), neither; (■) difficult.

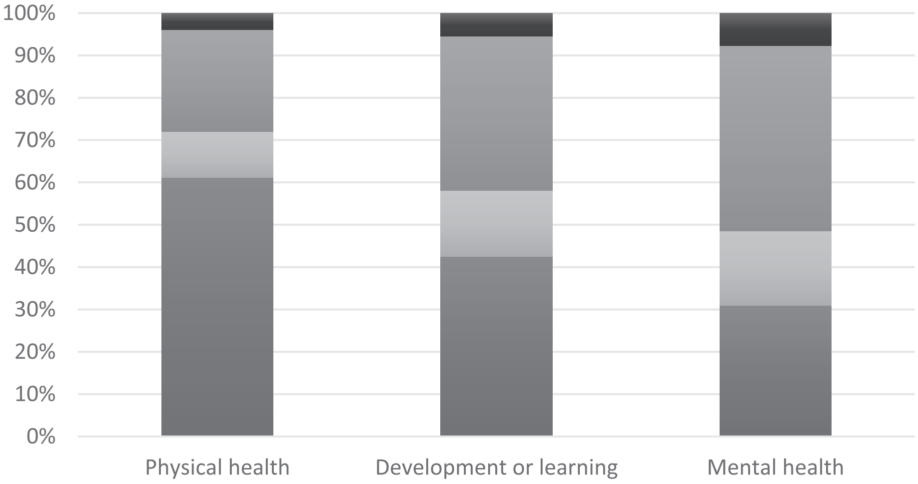

Fig 3 Proportion of carers believing child has had good assessment of health needs. (■), Agree; (■), neither agree or disagree; (■), disagree; (■) do not know.

domains (Fig. 3). While most carers reported that physical needs had been well assessed, only 43% of carers thought developmental needs and 31% mental health needs had been assessed well.

Carers were asked when they received a Medicare number or card for the child/young person in their care. While 31% had received this within 1 month of the beginning of the placement, over 50% waited more than 3 months, including 12% who waited more than 12 months. 27% of carers reported that the child/young person had experienced delays in accessing health care due to a delay with the Medicare number. Regression analysis found that where there had been three or more previous placements, the carer was more likely to receive the Medicare number by 3 months. There were no differences between age of child, carer socio-economic status or metropolitan versus regional location.

Sixty percent of carers reported paying out of pocket for a child/young person to receive a health service, most commonly GP appointments but across the range of services. With each increase in Socio-Economic Indexes for Areas quintile (representing higher socio-economic status), the chance that carers had paid out of pocket increased by 15% (RR 1.15, 95% CI 1.06–1.24). Of those carers who had paid, 78% reported that they had not been reimbursed.

Discussion

We aimed to survey carers' experiences of accessing health services for children and young people placed in their care, and we found high levels of health service use. Compared to Australian children overall, and similar to previous studies,[21,22] children and young people in OOHC have higher reported usage of GPs, paediatricians, speech therapy and mental health services.[23] However, like Melbye *et al.*[24] we demonstrated less frequent dental visits for children in OOHC. The National Child Oral Health study found that 10.3% of Victorian children aged 5–14 years had never had a dental visit,[25] compared with 18% of those similarly aged (4–12 years old) in this study.

These findings should be considered in the context of state and federal guidelines that recommend all children and young people who enter OOHC should have health assessments, including routine optometry, dental and audiology assessments. While use was high for many of these services, our findings suggest there may be under-utilisation of some health services compared with recommendations, given the proportion of children/young people whose carers report they have never seen a dentist or GP. It is unclear from our study whether carers are under-reporting service use because they are unaware of services that have already been received in a previous placement or whether these assessments have indeed not taken place. The gap between need and service use across all domains of health may also be under-reported. Kaltner and Rissel[26] found that a group of Australian carers under-identified health needs compared to those identified by health professionals.

Mental health is the area of most concern for this population. Most carers thought that the mental health needs of children in their care had not been well assessed. The largest gap between carer-perceived need and service use was in mental health, and mental health services were the hardest to access. We know from previous studies that rates of mental health problems and the need for appropriate care are very high.[2,4,14] The limited demographic data about the children described in this study showed that 42% of those in foster care had at least three previous placements, increasing their likelihood of behavioural and mental health problems.[27] The difficulties accessing mental health services existed across metropolitan and regional areas, regardless of carer education level or socio-economic status. This suggests there may be systemic barriers for this population accessing mental health care that contribute to the perpetuation of the inverse care law, with those at greatest need least likely to get the care they need.

This study identified two potential barriers to health service access. Most publicly funded health services are paid for in full or in part through Medicare, which requires the child or young person's Medicare care or number. However, carers reported that it may take many months to receive the Medicare number for the child/young person in their care, and that for more than a quarter of children, this had delayed their care.

While Medicare funds many of the needed health services, some require up-front payment with later reimbursement. Others are only partly subsidised through Medicare and require additional payment, usually paid for by the carer at the time of accessing care. Foster and kinship carers do receive an allowance (between $402 and $1639 fortnightly, depending on the needs of the child), which is intended to cover health along with all other costs of care; reports suggest that there is often a gap between allowances and costs,[20] especially for kinship carers.[28] Some out-of-pocket payments are reimbursable by Child Protection, but over half of carers reported paying out of pocket for health services for children/young people placed in their care, and just over 22% of those were reimbursed.

We followed up the survey with a qualitative study of 19 carers (9 kinship, 9 foster and 1 both kinship and foster) to understand the barriers and enablers in more detail.[29] The follow-up study confirmed that paediatric and mental health care were the hardest to access and that obtaining Medicare numbers and out-of-pocket costs were barriers to health care. Additional barriers identified through the interviews included the complex consent and authorisation environment, a lack of publicly funded services, long waitlists at those that do exist and logistic challenges in attending appointments while still prioritising school and work.

This research with foster and kinship carers suggests that more needs to be done to facilitate both routine health assessment upon entry to care and access to trauma-informed health-care services to meet identified need. Existing services could reconsider how they might prioritise children in OOHC and deliver health care with greater flexibility – something that the increased provision of telehealth in Australia might facilitate. The development of state-wide integrated primary care, paediatric and mental health service delivery models could also simplify pathways to care and improve access. The complexity of health-care navigation and limitations on resources could be ameliorated by a clinical workforce sitting alongside CP/OOHC that delivered health screening, triaging to universal services or dedicated multidisciplinary assessment teams as needed.

Strengths

This is the first Australian study to explore and quantify factors associated with better access to health care for children and young people placed in OOHC. Our carer population was representative across most demographic variables and covered the state widely. Although selection bias was a risk (those with negative experiences or with greater regard for health may have been more likely to complete the survey), the range of responses across most questions suggest that this is not a significant problem.

Limitations

While the study cohort is broadly representative, the respondents comprise only approximately 5–10% of carer households, with kinship carers under-represented. This limits the generalisability of the findings. Health service utilisation figures are also likely to be somewhat under-reported, as they rely upon the foster carers' knowledge of past health visits, and carers did not always know. Need for health services may also be under-reported.

The closed-ended questions in the survey also limit the depth of understanding of the experiences of carers, as well as prevent gathering of additional barriers and facilitators to health service utilisation. It was for this reason that we followed the survey with qualitative research to understand the different experiences of foster and kinship carers in accessing health services and to explore both barriers and facilitators to health service utilisation for children and young people in OOHC. Future research is needed to build an evidence base around enablers of health-care access and timely and appropriate health-care delivery to those in OOHC.

Conclusion

Victorian foster and kinship carers report high levels of health service use for children and young people in OOHC, although use may still not match levels of need. Most carers thought that mental health needs had not been well assessed. Mental health services were also the most difficult to access. Specific barriers that could be addressed to facilitate health service use include timely access to a Medicare number and financial support. The development of integrated paediatric health care and clinicians co-located with Child Protection could also assist.

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References

1. Australian Institute of Health and Welfare. Child protection Australia 2018-19. *Canberra*: AIHW; 2020. https://www.aihw.gov.au/reports/child-protection/child-protection-australia-2018-19/contents/table-of-contents.
2. McLean K, Little K, Hiscock H, Scott D, Goldfeld S. Health needs and timeliness of assessment of Victorian children entering out-of-home care: An audit of a multidisciplinary assessment clinic. *J. Paediatr. Child Health* 2019; **55**: 1470–5.
3. Egelund T, Lausten M. Prevalence of mental health problems among children placed in out-of-home care in Denmark. *Child Fam. Soc. Work* 2009; **14**: 156–65.
4. Tarren-Sweeney M, Hazell P. Mental health of children in foster and kinship care in New South Wales, Australia. *J. Paediatr. Child Health* 2006; **42**: 89–97.
5. American Academy of Pediatrics. Health care issues for children and adolescents in foster care and kinship care. *Pediatrics* 2015; **136**: e1131–40.
6. Department for Education and Department of Health. *Promoting the Health and Well-Being of Looked-after Children: Statutory Guidance for*

Local Authorities, Clinical Commissioning Groups and NHS England. Department for Education and the Department of Health in England; 2015. https://www.gov.uk/government/publications/promoting-the-health-and-wellbeing-of-looked-after-children–2.

7 Department of Families, Housing, Community Services and Indigenous Affairs Together with the National Framework Implementation Working Group. *An Outline of National Standards for out-of-Home Care*. Canberra: Commonwealth of Australia; 2011. https://www.dss.gov.au/sites/default/files/documents/pac_national_standard.pdf.

8 Murray L, Tarren-Sweeney M, France K. Foster carer perceptions of support and training in the context of high burden of care. *Child Fam. Soc. Work* 2011; **16**: 149–58.

9 York W, Jones J. Addressing the mental health needs of looked after children in foster care: The experiences of foster carers. *J. Psychiatr. Ment. Health Nurs*. 2017; **24**: 143–53.

10 Blythe SL, Halcomb EJ, Wilkes L, Jackson D. Caring for vulnerable children: Challenges of mothering in the Australian foster care system. *Contemp. Nurse* 2013; **44**: 87–98.

11 Kerns SEU, Pullmann MD, Putnam B *et al*. Child welfare and mental health: Facilitators of and barriers to connecting children and youths in out-of-home care with effective mental health treatment. *Child. Youth Serv. Rev.* 2014; **46**: 315–24.

12 Chambers MF, Saunders AM, New BD, Williams CL, Stachurska A. Assessment of children coming into care: Processes, pitfalls and partnerships. *Clin. Child Psychol. Psychiatry* 2010; **15**: 511–27.

13 Octoman O, McLean S. Challenging behaviour in foster care: What supports do foster carers want? *Adopt. Foster.* 2014; **38**: 149–58.

14 Sawyer MG, Carbone JA, Searle AK, Robinson P. The mental health and wellbeing of children and adolescents in home-based foster care. *Med. J. Aust*. 2007; **186**: 181–4.

15 Withington T, Burton J, Lonne B, Eviers A. Carer perspectives of factors affecting placement trajectories of children in out-of-home care. *Child. Youth Serv. Rev.* 2016; **65**: 42–50.

16 Department of Health and Human Services, Victoria. *Victorian Handbook for Foster Carers*. Melbourne: State Government of Victoria; 2017. https://services.dhhs.vic.gov.au/victorian-handbook-foster-carers-word.

17 Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support. *J. Biomed. Inform.* 2009; **42**: 377–81.

18 Foster Care Association of Victoria. *Victorian Foster Carer Census*. Melbourne: Foster Care Association of Victoria; 2016. https://www.fcav.org.au/images/documents/FosterCarerCensus2016.pdf.

19 Foster Care Association of Victoria. *Foster Carer Snapshot March 2019*. Melbourne: Foster Care Association of Victoria; 2019. https://www.fcav.org.au/images/documents/FCAV_CSS_2019.pdf.

20 Foster Care Association of Victoria. *Carer Life Survey*. Melbourne: Foster Care Association of Victoria; 2018. https://www.fcav.org.au/images/CarerLife/CarerLife4Results.pdf.

21 Tarren-Sweeney M. Concordance of mental health impairment and service utilization among children in care. *Clin.* 2010; **15**: 481–95.

22 Knight EK, McDuffie MJ, Gifford K, Zorc C. Health service utilization of children in Delaware Foster Care, 2013-2014. *Del. Med. J.* 2016; **88**: 46–52.

23 Australian Institute of Family Studies. *LSAC Annual Statistical Report 2017*, Vol. **8**. Melbourne: The Institute; 2018.

24 Melbye ML, Chi DL, Milgrom P, Huebner CE, Grembowski D. Washington state foster care: Dental utilization and expenditures. *J. Public Health Dent*. 2014; **74**: 93–101.

25 Do LG, Spencer AJ. *Oral Health of Australian Children: The National Child Oral Health Study 2012–14*. Adelaide: University of Adelaide Press; 2016.

26 Kaltner M, Rissel K. Health of Australian children in out-of-home care: Needs and carer recognition. *J. Paediatr. Child Health* 2011; **47**: 122–6.

27 Rubin D, O'Reilly A, Luan X, Localio AR. The impact of placement stability on behavioral well-being for children in foster care. *Pediatrics* 2007; **119**: 336–44.

28 Victorian Ombudsman. *Investigation into the Financial Support Provided to Kinship Carers*. Melbourne; 2017. https://www.ombudsman.vic.gov.au/our-impact/investigation-reports/investigation-into-the-financial-support-provided-to-kinship-carers/#related-information.

29 McLean K, Clarke J, Scott D, Hiscock H, Goldfeld S. Foster and kinship carer experiences of accessing healthcare: A qualitative study of barriers, enablers and potential solutions. *Children and Youth Services Review.* 2020; **113**: 104976. http://dx.doi.org/10.1016/j.childyouth.2020.104976.

Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Carers' Voices Survey: health.

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Foster and kinship carer experiences of accessing healthcare: A qualitative study of barriers, enablers and potential solutions

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ABSTRACT

Children living in out-of-home care are known to have more health needs than same-aged peers. Routine health assessment with subsequent management of need is recommended by health experts. In Victoria, Australia, the out-of-home care system relies upon home-based care through kinship (with family) and foster carer placements, placing some of the healthcare access and utilisation burden upon foster and kinship carers. This paper explores the experiences of Victorian foster and kinship carers accessing timely health assessment and ongoing healthcare for a child placed in their care; identifying barriers and enablers. Through interviews with 19 carers, we found that while carers play a significant role in facilitating healthcare, it is often difficult to navigate a complex health system especially while concurrently navigating the child protection system. Although some carers had faced few challenges, barriers were frequently reported at every step in accessing healthcare: receiving necessary paperwork (including child Medicare numbers); obtaining past medical history including immunisations; knowing what appointments were required; gaining appropriate authorisation for healthcare; identifying appropriate healthcare services; accessing timely appointments; attending appointments and paying for services. Carers had often been strong advocates for children in their care and had found support from case managers or carer support workers to be instrumental in enabling healthcare. Carers identified potential solutions to help children in their care receive timely healthcare.

1. Introduction

In Australia and similar jurisdictions, the child welfare system relies upon home-based care for children who have been removed from their primary caregivers by statutory authorities due to substantiated concerns about child abuse and/or neglect. On June 30, 2019, in Victoria, Australia, 8490 children and young people were in out-of-home care (OOHC) – also known as "foster care" or "looked after children and young people". 92% of Australian children in OOHC in 2017 were in home-based care, including 52% in relative/kinship care and 39% in foster care placements (AIHW, 2020). This model of care places a certain amount of the day-to-day care burden upon foster and kinship carers, including facilitating attendance at healthcare appointments for the children and young people in their care. While foster carers will have support from their foster carer agency ("agency"), kinship placements are typically initially managed directly by statutory authorities and receive less support Commission for Children and Young People (CCYP, 2019).

1.1. *Health needs in out-of-home care*

Children and young people in OOHC have higher rates of health problems than the general same-aged population, across all domains of health: physical, developmental, psychosocial and mental health (Deutsch & Fortin, 2015; Deutsch et al., 2015; Nathanson & Tzioumi, 2007). These health problems can contribute to placement breakdown (Brown & Bednar, 2006), which in itself has negative impacts upon health (Rubin, O'Reilly, Luan, & Localio, 2007). Australian and international child health experts recommend routine early health assessment with ongoing review of health needs following entry to OOHC, to enable the appropriate management to take place (AAP, 2015; Department for Education and Department of Health, 2015; RACP,

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2006). The Australian federally endorsed National Clinical Assessment Framework, designed to support the National Standards for Children and Young People in Out-of-home Care, recommends an initial health check within 30 days of entry and a comprehensive health assessment within 3 months of entry to OOHC (CHWS, 2011; FaHCSIA, 2011), including dental, vision and hearing assessments.

However, despite policy and health expert agreement regarding the need, few Australian jurisdictions have successfully implemented routine timely health assessment and ongoing healthcare (Vimpani, Boland, Barr, & Marshall, 2012) and the intended monitoring of health checks has not been possible due to lack of data (AIHW, 2019). Barriers that have emerged from the existing international research include insufficient availability of services (Murray, Tarren-Sweeney, & France, 2011; York & Jones, 2017), lack of clarity around roles, responsibilities and authorisation of the adults and agencies involved (Blythe, Halcomb, Wilkes, & Jackson, 2013), bureaucratic delays and the challenges of navigating a complicated health system (Blythe et al., 2013; Jaudes, Champagne, Harden, Masterson, & Bilaver, 2012; Kerns et al., 2014). The foster or kinship carer plays an important role in facilitating healthcare, and faces the logistic difficulties inherent in attending appointments including time, parking, child-care for other children in their care, as well as potential out-of-pocket financial costs (Chambers, Saunders, New, Williams, & Stachurska, 2010; Kerns et al., 2014; Murray et al., 2011; Raman, Reynolds, & Khan, 2011).

1.2. *Australian health service context*

While Australian Child Protection (CP) and OOHC services are state-based, health services are delivered with a mix of federal, state and local government funding, supplemented by privately funded services (resulting in out-of-pocket costs to the consumer). Medicare is a federally funded universal health care insurance scheme that subsidises the majority of primary and secondary care medical services: “bulk-billed” community based primary and secondary medical services are fully covered by Medicare. Other providers operate within private practice and Medicare rebates partly cover the cost, leaving the patient to pay the remaining costs. Non-medical Medicare subsidised services often have a capped number of visits per annum. Table 1 summarises the funding arrangements for differing services; it should be noted that private providers exist across all health service types.

While some programs have endeavoured to address the need for health assessment for children and young people entering OOHC in Victoria (McLean, Little, Hiscock, Scott, & Goldfeld, 2019; Milburn, Lynch, & Jackson, 2008; Tremellen & Van Doorn, 2012), none have been state-wide.

1.3. *Previous literature*

Several studies have explored the experience of kinship and foster carers in accessing health services for children in their care, some of which focused on access to mental health services. These studies have identified challenges in the US, the UK and New Zealand with inadequate service provision across paediatric and mental health services, long waiting lists and out-of-pocket costs to carers (Bonfield, Collins, Guishard-Pine, & Langdon, 2010; Callaghan, Young, Richards, & Vostanis, 2003; Hayes, Geiger, & Lietz, 2015; Murray et al., 2011; York & Jones, 2017).

Very few papers explore the experiences of Australian carers accessing health services for children and young people in OOHC; those we found focused mostly on mental health. One survey of carers found they wanted better access to General Practitioners and mental health services to respond to mental health and behavioural needs (Octoman & McLean, 2014). Another found carers reported difficulty accessing mental health services in a timely way (Sawyer, Carbone, Searle, & Robinson, 2007). A qualitative study of kinship and foster carers in the state of Queensland that explored factors affecting placement

Table 1
Summary of funding sources for health services.

	Federal funding		State funding		
	Medicare	National Disability Insurance Scheme (NDIS)	Department of Health	Department of Education	Other
Medical – primary care	Yes				
Medical - specialists	Yes		Community health clinics; hospital outpatients		
Speech therapy, physiotherapy, occupational therapy (0–6yo)	If on chronic disease management plan (5 visits per year)	Yes	Community health clinics		
Speech therapy, physiotherapy, occupational therapy (school age)	If on chronic disease management plan (5 visits per year)	Yes		Limited through schools	
Dental	Means-tested for children		Community health centres	Visiting dentist at some schools	
Mental health	Capped 10 psychology sessions annually	Youth mental health centres	0–6 years community health centres; tertiary mental health teams	Limited capacity within schools	Specific OOHC service (Take Two)
Optometry	Yes		Subsidised glasses		
Audiology	Yes		Community health clinics		

trajectories noted that carers reported difficulties accessing resources, including counselling and that this could contribute to placement breakdown (Withington, Burton, Lonne, & Eviers, 2016). To our knowledge, there have been no studies aiming to understand Australian carer experiences accessing healthcare.

1.4. Aim

The purpose of this study is to understand foster and kinship carers' experiences of accessing timely health assessment and ongoing healthcare for children entering out-of-home care in Victoria, and to identify barriers to timely health service access and potential solutions.

2. Methods

2.1. Study design

This was a phenomenological qualitative study with both telephone semi-structured interviews and focus groups, designed to complement and expand upon the quantitative information gathered from an on-line survey of 290 Victorian foster and kinship carers (currently under review).

We chose to use telephone interviews rather than face-to-face interviews for several reasons, including reduced potential risks with home visits, increased flexibility for interview times and reduced costs. Our focus on experiences accessing healthcare, including barriers and enablers to access, meant that our interview schedule did not include highly sensitive questions or topics and we did not need to identify or record non-verbal data. While telephone interviews can potentially hamper the establishment of rapport and interpretation of non-verbal communication (compared with face-to-face interviews), we felt that the benefits outweighed potential detractions.

We held focus groups following the completion of the interviews, after preliminary data analysis had occurred. The purpose was two-fold: firstly, member-checking of the results from both the survey and initial impressions from the interviews, and secondly, an opportunity to brainstorm solutions to facilitate access to healthcare for children and young people placed in care.

2.2. Setting and participants

Participants for the study were recruited from participants (n = 290) in the *Carers' Voices: Access to health for kids in care* study (paper currently under review). These Victorian foster (n = 239, around 24% of all Victorian foster care households) and kinship carers (n = 51, 1.4% of all Victorian kinship households) had completed an online, close-ended survey about their experiences as a foster or kinship carer accessing health services for children or young people (0–17 years) placed in their care. While the survey was able to be completed anonymously, participants were asked at the end of the survey if they were interested in taking part in a telephone interview and/or a focus group. Those who were interested (59% of kinship carers (n = 30) and 41% of foster carers (n = 98) for an interview; 47% of kinship carers (n = 24) and 28% of foster carers (n = 67) for focus group participation) provided contact details. All participants had cared for a child in statutory care in Victoria, Australia; informal placements were not included.

We purposively recruited to the telephone interviews so that we might hear from carers who had experience caring for children in the age range of interest (0–12 years), for long enough that they may have been involved in healthcare management (i.e. > 3 months). We chose to focus on the younger age group rather than adolescents, as healthcare management becomes more complex as independence and autonomous decisions increase. We sought out carers with a range of time spent as a carer, and we approached both carers who thought that the child in their care had a good health management plan and those who did not. We ensured that we included some carers who had experienced the Pathway to Good Health program for a child in their care. This program provides multi-disciplinary comprehensive health assessments for children in out-of-home care and is available for free (subsidised by the Victorian government) in some parts of Melbourne and Victoria. As we were interested in any areas of difference in experiences for kinship and foster carers, we aimed to recruit 10 kinship and 10 foster carers to the telephone interviews. Due to the likely large overlap of experiences between kinship and foster carers, we anticipated that the total of 20 interviews would be adequate for data saturation.

A member of the research team (JC) approached carers who had indicated their interest in the survey and who met the selection criteria, usually via telephone, to explain participation in the study and to set up a time for an interview. One carer approached was too unwell to participate, and one other initially agreed but then was not able to be contacted. Otherwise, those carers who responded to the request for an interview were included until recruitment was complete. A Participant Consent and Information Form was emailed to the participant at least a week prior to the interview. Verbal consent was obtained at the beginning of the interview and recorded by the interviewer (JC).

Carers who had participated in the telephone interviews and stated that they might be willing to also participate in a focus group, together with carers who had identified on the survey that they were interested in joining a focus group, were approached by JC to recruit to either a foster carer or kinship carer focus group. Participant consent and information forms were again distributed at least one week prior to the focus group and consent was obtained on the day of the group. Focus groups were hosted by the Foster Care Association of Victoria and Kinship Carers Victoria and ran for approximately 90 min.

All participants were given pseudonyms.

2.3. Data collection

We developed a semi-structured interview schedule with open-ended questions to elicit carer experiences in facilitating healthcare for children in their care (see Appendix A). Specific prompt questions were developed, aligned with barriers and enablers previously identified in the literature and initial survey, to ensure that these could be explored. The semi-structured nature of the interviews ensured that the interviewer could clarify and follow up on comments made by participants that may have been unclear. The interview schedule was reviewed by all of the research team and was piloted and refined with several carers who did not take part in the final study.

A single research assistant conducted all the interviews (JC) which lasted between 22 and 59 min, with a mean and median length of 38 min. Interviews were recorded and transcribed by an external transcription provider. Transcriptions were checked for accuracy by the primary researcher (KMcL).

Two focus groups followed preliminary analysis (see below) of the data from the interviews to identify major themes. We had a focus group schedule to guide discussion with participants. The main discussion points were twofold: firstly, clarifying whether the experiences, barriers and enablers to accessing healthcare were consistent with the experiences of the focus group participants. Secondly, we gave the carers an opportunity to brainstorm changes or improvements that would facilitate timely access to health services for children or young people placed in their care. Both KMcL and JC attended the focus groups, with preliminary findings presented by KMcL and discussion facilitated by both researchers. Notes were taken during the focus groups, which were also recorded. Transcriptions were checked for accuracy by KMcL, using the notes as an aid.

2.4. Data analysis

The interview transcripts were read when transcripts were being checked for accuracy, which provided familiarity. Interviews were coded using NVivo 12 software. We used a deductive approach, based on the barriers and enablers that had been identified in the literature review and in the Carers' Voices online survey. We developed a preliminary code-book prior to starting coding, and more codes were added as needed. KMcL and JC both coded all the interviews independently prior to reviewing discrepancies together. The focus group provided some member checking and expanded the reach as none of the focus group participants had been interviewed. Following coding, themes, sub-themes, and categories emerged through scrutiny of the coded data.

2.5. Research team and reflexivity

KMcL was the chief investigator for the study who designed the study, developed the interview and focus group schedules, co-facilitated the focus groups, checked transcripts for accuracy against the recorded interviews and coded and analysed all transcripts. KMcL is a paediatrician, whom some interview participants had encountered with the children in their care through the Pathway to Good Health program. The project supervisors, SG, HH and DS, provided oversight of the study design, analysis and interpretation, and also provided an 'outsider' perspective. A research assistant, JC, undertook recruitment of participants, telephone interviews, co-facilitated the focus groups and double-coded all interviews to add rigour. JC did not have previous experience with foster or kinship carers and provided an 'outsider' perspective which helped ensure that assumptions were not made during interviews and removed the risk of a previous clinical relationship affecting the answers provided in interviews.

2.6. Ethics

This study was approved by the Royal Children's Hospital Human Research Ethics Committee (HREC/18/RCHM/342).

3. Results

While 20 interviews were conducted, it became apparent that one kinship carer had been caring for a child informally, not through statutory authorities. This interview was excluded from analysis. However, since one carer was both a foster and kinship carer, there were ten interviews with each type of carer.

The demographic details, carer experience and pseudonyms of the nineteen included participants are shown in Table 2.

The foster carer focus group included 8 foster carers, none of whom had been interviewed. Attempts to have a kinship carer focus group were unsuccessful, with only one of four recruited kinship carers who agreed to participate actually attending on the day. As she had already participated in an interview, we based our focus group findings only on the foster carer focus group.

3.1. Carers are experienced in accessing a range of health services for children placed in their care

All carers interviewed had accessed health services for children or young people in their care. All carers mentioned General Practitioner (GP) and dental services and the majority discussed paediatricians, other medical/surgical specialists, audiology, optometry and mental health services. Carers were mostly positive about the health professionals they had encountered; there were only a couple of examples of lower-than-expected quality of care. While some carers had found accessing health services straightforward, it was more common to have had difficulties.

3.1.1. General practitioners

Appointment availability with GPs was generally easy. A few carers cited a pre-existing relationship with their GP practice as helpful in facilitating care. About half of carers, including Tracy and Frank, spoke positively about the support received from their GP:

> *We've always found as soon as we mention the kids are in foster care, they will make things available.* (Tracy, foster carer)
> *Our GP is very good. He takes a lot of stress off us looking after ourselves. And also understanding where we are with the kids and what problems the kids have.* (Frank, kinship carer)

Only one carer, Wendy, had a negative experience with a GP, which occurred when she took children in her care to a GP she had not met before:

> *We're supposed to take them to a GP to get a form filled out, but you're talking about a GP that's never met these children before. So, they do the basics, they do height, weight, listen to their heart, ask the kids couple of questions and say, "Yeah, they're in good health."… it's a GP that's never seen them, he's just doing the physical rundown. So that doesn't give you anything. That's just ticking the box with the department.* (Wendy, foster and kinship carer)

3.1.2. Paediatric, dental and allied health services

Carers frequently mentioned paediatricians and several described

Table 2
Demographics of interview participants.

Carer type	Gender	Age (years)	Years as carer	Number of children cared for	Metro/regional	Considered child had good health management plan	Pseudonym
Foster	Female	46–50	1–5	6	Not metro	Neither agree/disagree	Nancy
Foster	Female	51–65	1–5	5	Metro	Agree	Heather
Foster	Female	36–45	1–5	5	Metro	Neither agree/disagree	Tracy
Foster	Male	51–65	1–5	9	Not metro	Strongly agree	Brian
Foster	Female	36–45	1–5	15	Metro	Strongly disagree	Kimberley
Foster	Female	46–50	1–5	9	Metro	Strongly disagree	Kelly
Foster	Female	36–45	1–5	20	Not metro	Disagree	Jennifer
Foster	Female	36–45	1–5	22	Metro	Strongly disagree	Amanda
Foster	Female	18–35	> 10	12	Metro	Agree	Courtney
Kinship	Female	18–35	1–5	1	Metro	Agree	Emily
Kinship	Female	> 65	1–5	4	Not metro	Agree	Gloria
Kinship	Female	46–50	1–5	3	Metro	Don't know	Rebecca
Kinship	Female	51–65	6–10	1	Not metro	Strongly disagree	Patricia
Kinship	Female	> 65	6–10	3	Metro	Strongly agree	Irene
Kinship	Female	> 65	> 10	4	Metro	Strongly disagree	Sandra
Kinship	Female	51–65	> 10	1	Metro	Agree	Deborah
Kinship	Female	51–65	> 10	3	Metro	Don't know	Mary
Kinship	Male	> 65	> 10	5	Metro	Neither agree/disagree	Frank
Foster & kinship	Female	51–65	> 10	60	Metro	Strongly disagree	Wendy

their role as managing medications and overseeing care. There was often a long wait to see a paediatrician, especially within publicly funded services.

> *…His behaviours were quite severe, and he needed to see a paediatrician, but it was really a long wait to get in…* (Emily, kinship carer).

Long waits for appointments or difficulties finding available services were also described for speech pathology, dental and audiology services.

> *I guess the dental situation is an example of that, just that you can get an appointment, but how long do you have to wait?* (Heather, foster carer)
> *There's no public hearing facilities in our area that we know of.* (Brian, foster carer)

3.1.3. Mental health services

The greatest difficulty for carers was accessing mental health services. Carers described accessing mental health services using phrases such as *very, very hard; a significant hurdle; the worst we have to deal with*. Almost all carers discussed the need for counselling and/or psychology services, and several felt the child's needs had not yet been met. Barriers included a lack of services that were appropriate for the needs of children and young people in care and that offered sufficiently frequent contact and support, inadequate funding for the high rates of need, and difficulties getting consent for mental health care from the legal guardian as per the various child protection court orders.

Heather had experience with a local state-funded mental health therapy program specifically designed and funded for children/young people in OOHC but had concerns about the fixed-term nature of the program and the long wait before it began:

> *The big one is the access to the Take Two therapy. That was very hard to obtain. … the time between the identification of the program and him accessing the program would have been 12 months or something.* (Heather, foster carer)

3.2. Carers expect health needs to be met

Carers clearly expressed that they wanted children and young people placed in their care to have their health needs met in a timely way. While a handful of carers had found things uncomplicated, there were many ways in which achieving good healthcare had been challenging. Eleven of those interviewed used words indicating strong emotions around the difficulties of navigating healthcare in this setting: *painful; bloody hard work; ridiculous; stressful; toxic; frustrating; challenging; nightmare; angry; resentful; lonely.* Most expected that there would be support from either the Victorian Department of Health and Human Services (DHHS) or their agency (if they had one) at each stage including paperwork, arranging and funding appointments and treatment, but many felt that they had carried more of the burden than they thought reasonable and that the children and young people were not receiving what they deserved.

> *When they first come into your care, that is when you need all the support that you can get, and that's where I find it fails.* (Mary, kinship carer)
> *I scratch my head, because … do they not have a duty of care to this child whom they have placed in my care, a legal obligation to make sure that her emotional needs are met? … I see it as criminal negligence. They're legally bound to make sure all her needs are met.* (Patricia, kinship carer)

3.3. Accessing health services: barriers at each step

Many different process elements were identified as carers talked about accessing health services for children and young people in care, as outlined below. Barriers to timely and appropriate care were identified at each of these stages.

3.3.1. Access to the Medicare number (or card) of the child/young person.

Most GP, dental, audiology and optometry services are Medicare funded (at least in part) and providing a Medicare number is routine when attending an appointment to facilitate accurate Medicare billing. It was very common for children/young people to arrive in placement without a Medicare number. 13 carers shared experiences with delays in receiving the (correct) Medicare number for the child or young person in their care, which had an impact on accessing health services. Some children missed or waited longer for appointments because the carer did not know the Medicare number and the health service refused to make an appointment without one.

> *We actually had to hold off seeing optometrist, hearing and GP because we didn't have a Medicare number that was usable…[for] three months* (Tracy, foster carer)
> *It's very difficult to get an appointment for a child without a Medicare card.* (Sandra, kinship carer)

Some other carers had been required to pay for services with the assumption that it would be repaid when the Medicare number was available. In contrast, the minority of carers who had received a number when the child arrived reported that it was straightforward to organise appointments.

> *Once you've got the right details it's easy.* (Sandra, kinship carer)

Carers showed ingenuity in how they had found out the correct Medicare number. Some used relationships with extended family (kinship) or with other carers who had a sibling of the child in their care; others used networks within the health system to look up the number for them. However, if the child had entered care before having a Medicare number, the application process (which requires parental consent and involvement) was very slow.

Carers also agreed that having a physical Medicare card (and not just the number) was optimal for health service access. Some carers had experienced health services doubting their authority to bring a child to an appointment without the physical card; one reported feeling uncomfortable having to explain the child's social history to the reception staff in earshot of the child(ren) (to justify why they did not have the card).

3.3.2. Obtaining the past medical history of the child/young person

While a couple of carers had received some health information about the child in their care, almost all carers reported that they had not received much information about the child's previous health history, appointments or immunisations.

> *I was given nothing at the start. A bit later down the track I was given this folder with all the information in it….. Probably … More than six months [later] I think. It was a bit horrendous.* (Gloria, kinship carer)

Some kinship carers were at an advantage with family knowledge about the child's and family's medical history, especially if they had a pre-existing relationship with the child before they entered care.

> *Any information I got was through the mother, that's my daughter. Basically, because they were with me from day dot [birth], theoretically there was nothing really to be given to me.* (Deborah, kinship carer)

Foster carers also reported that usually very limited health information arrived with children or was provided with time, and this impacted on the care they could provide. Some carers felt they had to strongly advocate to be provided with any detail.

> *I got zero information. I wasn't told whether he was breast feeding or on formula, anything about him. I just literally was handed a baby and then they disappeared. So, it was like giving birth to a 12 month old baby and*

> *then taking it from there. And trying to track any information by the Department about what professionals he had seen previously was just this monstrous task. We just never got anywhere with it.* (Kelly, foster carer)

Carers found it difficult when healthcare providers were asking for information and they did not know the history.

> *Even when they go to hospital "What's her history?" Again, it's like, "Well, I don't really know. It might pay to ring the Children's [hospital] and find out from them because we're not given their medical history until they're actually in our care permanently."* (Rebecca, kinship carer)

Immunisation information was a specific area of health information that a third of carers described specific difficulties accessing, with privacy being cited as the explanation. This had had flow-on effects for some children with enrolment in early childhood education due to government policy mandating immunisation for all children enrolled.

> *We even got a letter from childcare saying that we need to remove the children until we can prove their immunisation status. That was hard.* (Kimberley, foster carer)

3.3.3. Knowledge of what appointments might be needed (access to guidelines)

Carers had different experiences with guidance around health assessments and healthcare. Some carers received no guidance at all and had no knowledge of any requirements for health assessment. Around half of carers interviewed, like Kimberley, were aware of guidelines about various health assessments that were required – at entry, and annually thereafter:

> *It's actually a requirement from D[H]HS, which goes to your agency, to get an assessment at your GP, to get a medical assessment within just a few weeks of the children coming into your care….you are expected to get a medical check for the child, dentist, optometrist, and go to the GP.* (Kimberley, foster carer)

3.3.4. Authorisation to make health decisions

While kinship carers generally felt that they made all health decisions themselves, foster carers almost universally described a decision-making process that involved their carer support worker/agency, the DHHS, and at times birth families. Unless a child has been placed in permanent care with guardianship granted to the carer, decision-making authority for most legal orders sits with either the parent or the DHHS. The need for parental consent was understood by some carers, but the process of gaining consent was rarely executed quickly. Carers frequently described delays in many months from identifying a child needed a service to approval for that service. Some of these delays were worsened by caseworker turnover or a lack of allocated case manager.

> *We requested a paediatric review. And there was nothing done with that. We changed child protection workers, and the first worker apparently had submitted the paperwork, and by the time the new CP worker was appointed, apparently it had expired. And then getting approval back through never happened. So, she missed out on a paediatric review.* (Amanda, foster carer)
>
> *I vaguely remember there being an appointment earlier, but at the time, I knew it would be a rather more complicated process, so I asked for one about two weeks later. It didn't delay it significantly, but if I didn't have to ask anyone, the kid would've been in within a week and had the surgery a week after that. It ended up being about two months from start to finish.* (Courtney, foster carer)
>
> *For example, a psychologist would say, "I need written approval from a parent before we can proceed." So then I would have to tell my case manager at my agency, then she would have to contact the Department. Then the Department would have to contact the parent. And then the parent would have to get back and it would have to go all the way back. And so, if any one person was on leave or just delayed doing it or forgot about it, then we'd have to go through the whole chain again to find out what was happening. So, it meant like a simple request or something could take weeks.* (Kelly, foster carer)

Even in circumstances requiring urgent (though not life-saving care) carers described care sometimes being delayed by hours while consent was being sought or experiencing anxiety that treatment might be delayed due to the uncertainty of the process.

> *We were at midnight before we really got any relief for her, even pain medication. Yeah, it just makes it so difficult and long-winded, and then in the meantime the children are actually in pain or can be quite traumatised by the whole situation.* (Wendy, foster and kinship carer)

Some carers took matters into their own hands and proceeded with medically recommended treatment, depending on circumstances and their perception of the urgency of care.

> *In the end, I made all the decisions simply because I found it too frustrating trying to work through DHHS and any of their agencies because you don't get a call back to see whether you are allowed to do it. And so, right or wrongly, I made the decisions and took them to appointments. … So I figure they can sue me or take me to court but the children come first.* (Sandra, kinship carer)

Carers found it frustrating that their own assessment of a child or young person's needs, or even those of a healthcare professional, had to be confirmed by someone without health qualifications before they could proceed with providing care.

> *We had to wait three weeks for the parents to give permission. And I mean, I just said unless they're paediatricians or medical experts, which I don't believe they are, I'm going to give this medication to this child who desperately needs it. Sue me!* (Foster carer, focus group).

This was particularly evident for mental health concerns, as Brian and Courtney discussed:

> *We've wanted to take [him] and we were willing to pay for our own and willing to take him and D[H]HS said No, you're not going to do that…. And within two months we finished the placement because it was just beyond our capabilities to handle the child.* (Brian, foster carer)
>
> *There's local psychologists and there's a particular good one that the school recommended, but we just kept getting told no, it wasn't suitable.* (Courtney, foster carer)

The delays in receiving Medicare numbers described in 3.3.1 contributed to the lack of authorisation for healthcare; some health services would refuse to make an appointment without a Medicare number for the child. Some carers had experienced smoother processes due to having a letter of authorisation that satisfied the health services and enabled care to proceed.

Some foster carers also discussed that they took children placed in their care to the doctor more than their own children and more than they thought necessary, to satisfy the carer support agency and/or DHHS, for example, to be examined following a minor injury.

3.3.5. Identifying appropriate health services and arranging appointments

Carers were given the expectation that the health needs should and would be met through publicly funded health services, but described difficulty identifying appropriate services, in part due to lack of knowledge and in part due to lack of services. They were keen for support from either the DHHS case manager or their agency support worker in navigating the health services, especially when the healthcare was at the request of the DHHS, as in these comments from Sandra and Irene:

> *DHHS said well he had to go a hearing paediatrician in Frankston. And you can't make an appointment without the correct paperwork. They wouldn't facilitate the appointment, like make the phone calls and guarantee payment. And I couldn't do it because I had no paperwork to*

> *say he was in my care and I was acting as his in loco parentis.* (Sandra, kinship carer)
>
> *They wanted to know what disability they had, so I'd have to go and see a GP and I'd have to go and get information. They wanted to know, but they didn't go and offer help. No.* (Irene, kinship carer)

Lengthy wait times and infrequent appointments within the public healthcare system were identified across almost all service types. Carers felt there was an expectation that public health services would be used, but some carers reported that publicly funded services of a particular type simply did not exist in their area. This led to attempts to access the private system, with varying success in getting approval (and funding) to do so.

> *If there's no funding it's got to go on the free list, the free list - so then it becomes these long, ridiculous waiting list times. Then even when you get an appointment, the next appointment which if you were in private, you'd probably have it a week later, you might not get it for three months. There's just not the resources I guess in some cases unless you go private, and you can't go private…* (Wendy, foster and kinship carer)

3.3.6. *Attending appointments: logistic challenges*

Once health services were identified and appointment times scheduled, there were a variety of challenges in ensuring they were attended. The number of appointments recommended by the National Clinical Assessment Framework are a significant burden in a short space of time, described by one carer as *"challenging"* and *"hard on the kids… because you're trying to get to know them and then you take them round to all these doctors as well".* (Tracy, foster carer)

Logistic barriers to overcome included access to appropriate transport, cost of parking, distance to health services, challenges of co-ordinating the needs of all members of the household, the impact upon work (carer) and school (child) attendance.

> *They're pretty hard to get, so we kind of have to grab the first appointment we can and then work our lives around it kind of thing. So there's been many a times I've had to swap my shifts at work or what not to make an appointment.* (Jennifer, foster carer)

Some carers cited that unemployment was either a consequence of their role as a carer, or a factor that facilitated healthcare for a child in their care.

3.3.7. *Paying for appointments: financial costs*

Financial costs to carers were closely related to the complexity of both the health and child protection systems, including the difficulties obtaining appropriate paperwork, insufficient publicly funded health services, the need for approval for costs that might require reimbursement, and the reimbursement processes themselves.

Some carers had been 'bulk-billed' for various primary and specialist medical services, where the costs of the service are directly billed to Medicare with no out-of-pocket cost to the user/carer – as Deborah described:

> *She's been under the public system, so everything's been covered under Medicare* (Deborah, kinship carer)

A few carers reported positive experiences with the National Disability Insurance Scheme (NDIS) funding services that were needed, but significant delays and confusion about what might be covered by the NDIS were also described. However, the delays in receiving Medicare numbers (described in 3.2.1 above) contributed to financial costs experienced by carers, as health services would charge the carer in full up-front.

> *It's very difficult, because the children generally come with no Medicare card, so for carers you have to pay up front, because you don't have any details* (Kimberley, foster carer)

While bulk-billed services were sometimes available – usually for medical services – carers often wished to access "private" health services, with additional costs, to either shorten the wait time or simply to access the only available service near them (see Section 3.2.5 above). Even where Medicare rebates exist, there is often a gap between the rebate and the cost billed for the service. Even if reimbursement had been approved, this often required a level of cash fluidity for the carer to access the services, as described by Kelly:

> *They could never organise any system by which they could pay for the sessions and then recoup the money. So, I always had to pay $200 to go and see the psychologist, and then I had to get the bulk of it back on Medicare and then send in the request for the gap payment to the Department. So, that was an issue because I wasn't working at the time and it was $200 a fortnight to see the psychologist. They basically said, "You need to take cash along and pay for it."… Then send in the thing to get Medicare. But that's just dependent on me having $200 spare to do that.* (Kelly, foster carer)

Unlike medical services, the subsidies for allied health and mental health care within Medicare are capped, for example: a maximum of ten visits to a psychologist receive a rebate annually. Almost half of carers discussed the need for more mental health support than is routinely funded, due to the complex needs. Some carers had experienced difficulty in getting approval for such additional costs to be incurred or reimbursed. Several carers had accepted these costs themselves, with varying difficulty depending on their own circumstances.

> *We always make sure the kids get whatever treatment they need, you know. We'd go without to make sure they did, but you shouldn't have to.* (Deborah, kinship carer)
>
> *We've just paid out of our pockets. [We have been reimbursed] for some of them….but we don't bother claiming because it's too hard… and we're lucky enough that it's a discomfort. It's not detrimental.* (Amanda, foster carer)

Six mentioned that additional funding from the DHHS or their carer support agency had been instrumental in accessing services, for example:

> *We ended up getting support services … and they started helping pay for private people to see, like private psychologists or paying for his medical needs. So without that help, we were in the public wait list and the wait list was quite long.* (Emily, kinship carer)

Healthcare costs were not limited to attendance at appointments; paying for medications was another issue for some carers, as Deborah describes:

> *Medication costs me a fortune. The grand-daughter's on seven different medications a day, and the grandson, he's got four. Their healthcare card does cover some of it, so I'm only paying the base rate type-of-thing, but it's still out-of-pocket, nonetheless…All the medication every month out-of-pocket is about $90.00.* (Deborah, kinship carer)

The Healthcare Card mentioned by Deborah is a concession card that enables cheaper medicines and discounts for some health services. All children and young people in out-of-home care are eligible for a Health Care Card, but to apply for one requires the Medicare number and a birth certificate, so it can take many months before the carer has one; costs incurred while waiting may or may not be reimbursed.

3.4. *Enablers*

In the interviews and focus group discussions, several existing and/or potential facilitators of healthcare access were identified.

3.4.1. *Carers*

Carers are often remarkable advocates for the children and young people in their care. Phrases such as *"kept pushing", "constant* *reminding", "jumping up and down and inquiring and persisting and waiting" and "insisted"* reveal the enormous effort that was often required: it was clear that carers were highly invested in meeting the health needs of the child or young person. Where carers had capacity in their lives, whether time or financial, or had additional experience from previous carer roles, this often helped them feel that they were better able to facilitate great healthcare.

> *Well, we've been pretty lucky because I work part-time and my husband currently isn't working because we need to do all this for the children.* (Rebecca, kinship carer)
> *It helped because we'd been through the system before and we knew what was needed.* (Frank, kinship carer)

3.4.2. Support from DHHS and/or carer support agency

Healthcare for children and young people in OOHC can be facilitated with support provided by DHHS and/or a carer support worker. Such support included funding to enable access to private health services, prompt provision of Medicare numbers or paperwork, assistance arranging appointments, logistic support with transport to attend appointments (or even taking the child when the carer couldn't attend) and easy access to resolve urgent issues. Some of this support (especially arranging appointments and assisting with transport) was more often described as delivered by a carer support worker; kinship carers often were not connected with such a resource for many months or years. While carers were more likely to discuss times that they had not received good support, there were positive examples also mentioned.

> *I just called the DH[H]S and asked, said "I need a Medicare card for him"… he had a number on file.* (Emily, kinship carer)

3.4.3. Health service enablers

Carers identified the need for available and funded health services with appropriate clinician experience to deliver health assessments and treatment. Carers wanted children and young people in out-of-home care to be prioritised and not have to wait, in the hope that they might be able to start catching up with their peers.

> *Usually you're playing catch up. … The situation we have is that the child's been placed with you and they're already five, six, seven years behind in terms of their medical stuff. So that's why you need the priority. You've got to get them sort of up to speed.* (Focus group participant)

When healthcare delivery had some flexibility, whether with timing or location of appointments, it had been very helpful for carers.

> *They do attend our house and the children's services, so school and childcare to observe and to take their reports and then to have sessions with them.* (Courtney, foster carer)
> *I'm now doing dentist through the school, so that's made that a lot easier. They come twice a year, so I highly recommend that.* (Nancy, foster carer)

3.5. Suggested solutions

In the focus group discussion, it became clear that while common, not all of the frustrations and barriers were universally experienced by carers. Some carers had either found a work-around or simply had not the same experience. This seemed to be because many improvements suggested by carers already exist in policy but are inconsistently implemented in practice. Table 3 summarises the suggestions from carers, through interviews and the focus group, to improve healthcare for children and young people in OOHC.

4. Discussion

We aimed to explore the experiences of Victorian foster and kinship carers in accessing health services for children and young people placed in their care, and identify barriers, enablers and potential solutions. We found that carers strongly wanted the health needs of children in their care to be met in a timely way. While carers had considerable experience accessing a variety of health services, many had found navigating healthcare to be complex, and barriers to timely and appropriate healthcare were described by some carers at each step of the process.

Our findings are consistent with previously published studies from the UK, USA and New Zealand that identified out-of-pocket costs (Beck, 2006; Hayes et al., 2015; Murray et al., 2011; Pasztor, Hollinger, Inkelas, & Halfon, 2006), and long waiting lists for services (Murray et al., 2011; Pasztor et al., 2006; York & Jones, 2017) as frequently encountered barriers to healthcare. The struggle for adequate mental health care identified by many carers in our study confirms what was found in our on-line survey, where carers identified that mental health services were hardest to access. This echoes both interstate research within Australia (Octoman & McLean, 2014; Sawyer et al., 2007; Withington et al., 2016) and international research findings (York & Jones, 2017).

We identified for the first time that Australian carers, like their international counterparts, had experienced other difficulties including navigating consent processes(Leslie et al., 2005); having the authorisation to make health decisions(Hayes et al., 2015; Schneiderman, 2008); and obtaining past medical history for the child/young person in their care(Hayes et al., 2015; Schneiderman, 2008; Tremellen & Van Doorn, 2012). We also confirmed our survey finding that obtaining paperwork in a timely manner was a particular barrier for the carers in our study and found that this was for all relevant documents – e.g. Health Care Cards – not only Medicare cards.

However, despite the challenges, a minority of carers had experienced smooth processes and it became clear that different carers had received differing messages about some policies and procedures. This suggests inconsistent implementation of policy across both health and welfare sectors through the state, which is not unique to Victoria (Randsalu, 2018; Vimpani et al., 2012). Some of the solutions needed might therefore be addressed through implementation of existing policy rather than the development of new policy. Increased consistency of implementation might also address the articulated need for clear and consistent advice (from all parties involved) about the processes of accessing health services.

With the high rates of kinship care in Victoria, Australia, it was important to hear from kinship carers as well as foster carers. Many of the barriers to healthcare were experienced regardless of care type. Kinship carers were sometimes at an advantage with respect to knowledge of the health history for that child and family, where there was a pre-existing relationship with the child or young person. However, similar to the findings of Schneiderman et al., kinship carers more often reported a lack of support in navigating healthcare until they were allocated a support worker from an agency – which some described as taking years to occur (Schneiderman, Smith, & Palinkas, 2012). Support workers were usually a significant support in facilitating healthcare; consideration should be given to ensuring all children and young people have their placement supported in such a way from the beginning.

The findings in this study suggest that improvements could be made by all parties involved, to improve timely and appropriate healthcare delivery to children and young people in OOHC. Health services could potentially provide more flexibility in appointment times; manage waiting lists differently to prioritise those in OOHC; seek to employ appropriately skilled health clinicians and build capacity among frontline administrative and clinical staff to understand the additional needs of some of these children and young people. CP/DHHS could streamline the paperwork and documentation that facilitates healthcare

Table 3
Suggested solutions to enable timely and appropriate health service use.

Suggestion	Detail
Clear and consistent advice and support	● Clarity about how to access necessary health services ● Consistent responses from all parties (CP, agencies, health services) About health-related decision making – required appointments, available support, processes, etc. ● Consistent responses regardless of geographical area/CP office ● Consistent support to navigate and manage health
Simplified paperwork	Streamlined processes for paperwork upon entry so that children have Medicare and Health Care cards upon arrival in placement
Shared health information	Access to all relevant health information by carers, to enable them to provide the best care possible
Consent for assessment and treatment without delays	Clearer and faster processes for obtaining consent for healthcare, to minimise any additional delay to due OOHC status
Health routinely on care-team meeting agendas	Health needs to be included on all care team meetings
Routine assessment of health upon entry to care	To enable the identification of health needs
Improving access to appropriately trained clinicians	● Clinicians providing healthcare to children and young people in OOHC need to be familiar with the impact of childhood trauma ● Timely access may be facilitated by accessing privately funded services, in which case carers wanted approval and payment to do so ● Flexible health service delivery to minimise impact upon carers and interruption to schooling (including school-based delivery) ● Multiple services co-located for ease of access

and ensure that appropriate authorisation is given to the carer in a timely way, including Medicare numbers and Health Care Cards. Carer support agencies could ensure that they provide all carers with the information and support needed to attend the recommended health assessments for all children and young people who enter OOHC. Both CP and carer support agencies could consider a healthcare coordination role to assist carers with the navigation of these complex systems. Finally, some areas for improvement were identified that require input from policy-makers, legislators and magistrates. These include information sharing (currently under legislative transformation in Victoria) and consent for healthcare.

Our study has a number of strengths. It is the first to explore the carer experiences accessing health services in Australia including a focus on barriers and enablers to health service access. It is also the first study, to our knowledge, to include kinship carers to ensure their experiences were also heard. We were able to recruit carers from metropolitan and regional areas of the state, with positive and negative experiences of accessing healthcare and a diversity of caring experience. While all of the enablers were identified in a Victorian (Australian) context, given that barriers were consistent with findings in similar jurisdictions that also recommend routine early assessment, it is likely that these identified solutions would also have applicability beyond Australia.

However, we were recruiting from a sample that had expressed an interest in health issues (through their completion of the survey); we did not include non-English speaking carers, and only had two male participants. We also were not able to successfully undertake a kinship carer focus group, which meant that member-checking and brainstorming of solutions was limited to foster carers. The difficulty in recruitment of kinship carers to the focus group was in part due to lower numbers responding to the survey – while a higher proportion of kinship than foster carers were interested in participating in either an interview or focus group, the actual number was smaller. We hypothesise that, in line with USA research (Schneiderman et al., 2012), kinship carers in general have lower levels of support which meant that attending a focus group in person was challenging – three out of four carers that agreed to attend had challenges arise on the day that prevented their attendance.

While this research identifies barriers and enablers to health service access from the foster and kinship carer perspective, additional qualitative research to understand experiences, barriers and enablers for other key parties - including children and young people living in OOHC, the health clinicians, and CP and carer support agency staff - would support the design of robust solutions. This study focused on experiences for the younger cohort (mainly aged up to 12 years); it would be important in future research to explore the unique issues faced by the adolescents.

5. Conclusion

In this study we show that foster and kinship carers play a significant role in ensuring that health needs of children and young people placed in their care are met. Carers have high expectations and facilitate healthcare often at financial or other cost to themselves. The complexity of both the health and child protection systems mean that improvements are needed to facilitate timely communication of relevant and consistent information, navigation of health services and processes for authorisation of healthcare, and to reduce financial costs to carers. Increased capacity within health services for appropriately skilled care, delivered flexibly, is also required to enable children and young people in OOHC to have their health needs assessed and addressed without delay.

CRediT authorship contribution statement

Karen Mclean: Conceptualization, Funding acquisition, Project administration, Methodology, Formal analysis, Writing - original draft. **Jessica Clarke:** Investigation, Data curation, Formal analysis, Writing - review & editing. **Dorothy Scott:** Methodology, Supervision, Writing - review & editing. **Harriet Hiscock:** Supervision, Writing - review & editing. **Sharon Goldfeld:** Supervision, Writing - review & editing.

Declaration of Competing Interest

The authors declared that there is no conflict of interest.

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Appendix A

Carers Voices: access to health for kids in care

Carer interview schedule

Context:

You recently completed a survey about what it was like as a carer getting access to health services for a child placed in your care. In the survey, you told us you would be willing to talk to us more about your experiences.

> *[Carers will have been provided with a copy of the Plain Language Statement via email or mail. The interviewer will remind the carer about this statement and will let them know that they need to record consent over the phone. If the carer is comfortable, recording will start at that time, and the interviewer will read out the information statement over the phone. They will then obtain verbal consent for the phone interview. Carers will be reminded that they can stop the interview at any time, and they do not have to answer a question that they don't want to answer. Carer will be advised that the interview will last between 30 and 60 min.]*

Questions:

Experience as a carer:

1. Tell me about how long you have been a carer for, and how many children you have cared for.
2. You've had a child aged between zero and twelve years living with you in the last couple of years – can you tell me how long they lived with you for? Had they lived with other carers before you? (if so, for how long)?
3. (If appropriate – if have been a carer of more than one child) How many children in this age group would you say you have cared for in all your time as a carer?

Experiences accessing health services for a child in their care aged 0–12 years:

4. What sort of health services has the child been to while they have been living with you? [Specific prompts: GP/family doctor, paediatrician, dentist, hearing test, optometrist, maternal and child health nurse (if < 5yo)]
5. Tell me what it has been like for you getting the child to these appointments.
6. What things have helped you get a child to a health service, or made it easier for you?
7. What things have made it more difficult to get a child to a health service?

Roles, responsibilities and information:

8. There are often a few people involved in decision making for a child living in care. What sort of decisions about health care do you make for this child? How do you work out what to do?
9. Who else makes decisions about health care and health appointments for the child? Tell me about how that works? [Prompts: the case manager from DHHS, case worker from a foster care agency, the child, biological parents, the GP]

Health information:

10. Without going into specific details, what sort of information did you receive about health for this child/ or have you usually received for children in your care when they arrived? [Prompts: medications, allergies, behavioural difficulties, existing conditions, immunisations]. What has your experience been regarding the timing of when you get information?
11. What sort of information did you receive about what health visits the child needed to go to while they lived with you? (Who told you?)

Pathway to Good Health program:

12. Has a child in your care been part of the Pathway to Good Health program? If so, tell us what that was like for you? What would have made it better?
13. Do you have any other comments you would like to make about the health care for children living in foster and kinship care?

Interviewer thanks participant for their time and checks if they are also interested in being a part of the focus group.

References

American Academy of Pediatrics (AAP) (2015). Health Care issues for children and adolescents in foster care and kinship care. *Pediatrics, 136*(4), e1131–e1140. https://doi.org/10.1542/peds.2015-2655.

Australian Institute of Health and Welfare (AIHW) (2019). National Standards Indicators. Retrieved from https://www.aihw.gov.au/reports/child-protection/nfpac/contents/national-standards-indicators.

Australian Institute of Health and Welfare. (2020). *Data tables: Child protection Australia 2018-19Child Welfare series74*. Canberra: AIHW.

Beck, A. (2006). Users' views of looked after children's mental health services. *Adoption & Fostering, 30*(2), 53–63.

Blythe, S. L., Halcomb, E. J., Wilkes, L., & Jackson, D. (2013). Caring for vulnerable children: Challenges of mothering in the Australian foster care system. *Contemporary Nurse: A Journal for the Australian Nursing Profession, 44*(1), 87–98. https://doi.org/10.5172/conu.2013.44.1.87.

Bonfield, S., Collins, S., Guishard-Pine, J., & Langdon, P. E. (2010). Help-seeking by foster-carers for their 'looked after' children: The role of mental health literacy and treatment attitudes. *British Journal of Social Work, 40*(5), 1335–1352. https://doi.org/10.1093/bjsw/bcp050.

Brown, J. D., & Bednar, L. M. (2006). Foster parent perceptions of placement breakdown. *149 Children and Youth Services Review, 28*(12), 1497–1511.

Callaghan, J., Young, B., Richards, M., & Vostanis, P. (2003). Developing new mental health services for looked after children: A focus group study. *Adoption & Fostering, 27*(4), 51–63.

Chambers, M. F., Saunders, A. M., New, B. D., Williams, C. L., & Stachurska, A. (2010). Assessment of children coming into care: Processes, pitfalls and partnerships. *Clinical Child Psychology & Psychiatry, 15*(4), 511–527. https://doi.org/10.1177/1359104510375932.

Child Health and Wellbeing Subcommittee, Australian Population Health Development Principal Committee (CHWS) (2011). National clinical assessment framework for children and young people in out-of-home care (OOHC) Australia. Retrieved from http://health.gov.au/internet/publications/publishing.nsf/Content/ncaf-cyp-oohc-toc.

Commission for Children and Young People (2019). 'In our own words': Systemic inquiry into the lived experience of children and young people in the Victorian out-of-home care system (Melbourne).

Department for Education and Department of Health (2015). Promoting the health and well-being of looked-after children: Statutory guidance for local authorities, clinical commissioning groups and NHS England. England.

Deutsch, S. A., & Fortin, K. (2015). Physical health problems and barriers to optimal health care among children in foster care. *Current Problems in Pediatric & Adolescent Health Care, 45*(10), 286–291. https://doi.org/10.1016/j.cppeds.2015.08.002.

Deutsch, S. A., Lynch, A., Zlotnik, S., Matone, M., Kreider, A., & Noonan, K. (2015). Mental health, behavioral and developmental issues for youth in foster care. *Current Problems in Pediatric and Adolescent Health Care, 45*(10), 292–297. https://doi.org/10.1016/j.cppeds.2015.08.003.

Department of Families, Housing, Community Services and Indigenous Affairs together with the National Framework Implementation Working Group (FaHCSIA) (2011). An outline of National Standards for Out-of-home Care.

Hayes, M., Geiger, J., & Lietz, C. (2015). Navigating a complicated system of care: Foster parent satisfaction with behavioral and medical health services. *Child & Adolescent Social Work Journal, 32*(6), 493–505. https://doi.org/10.1007/s10560-015-0388-2.

Jaudes, K. P., Champagne, V., Harden, A., Masterson, J., & Bilaver, L. A. (2012). Expanded medical home model works for children in foster care. *Child Welfare, 91*(1), 9–33.

Kerns, S. E. U., Pullmann, M. D., Putnam, B., Buher, A., Holland, S., Berliner, L., … Trupin, E. W. (2014). Child welfare and mental health: Facilitators of and barriers to connecting children and youths in out-of-home care with effective mental health treatment. *Children & Youth Services Review, 46*, 315–324. https://doi.org/10.1016/j.childyouth.2014.09.013.

Leslie, L. K., Gordon, J. N., Lambros, K., Premji, K., Peoples, J., & Gist, K. (2005). Addressing the developmental and mental health needs of young children in foster care. *Journal of Developmental & Behavioral Pediatrics, 26*(2), 140–151.

McLean, K., Little, K., Hiscock, H., Scott, D., & Goldfeld, S. (2019). Health needs and timeliness of assessment of Victorian children entering out-of-home care: An audit of a multidisciplinary assessment clinic. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.14472.

Milburn, N. L., Lynch, M., & Jackson, J. (2008). Early identification of mental health needs for children in care: A therapeutic assessment programme for statutory clients of child protection. *Clinical Child Psychology & Psychiatry, 13*(1), 31–47.

Murray, L., Tarren-Sweeney, M., & France, K. (2011). Foster carer perceptions of support and training in the context of high burden of care. *Child & Family Social Work, 16*(2), 149–158. https://doi.org/10.1111/j.1365-2206.2010.00722.x.

Nathanson, D., & Tzioumi, D. (2007). Health needs of Australian children living in out-of-home care. *Journal of Paediatrics and Child Health, 43*(10), 695–699. https://doi.org/10.1111/j.1440-1754.2007.01193.x.

Octoman, O., & McLean, S. (2014). Challenging behaviour in foster care: What supports do foster carers want? *Adoption & Fostering, 38*(2), 149–158. https://doi.org/10.1177/0308575914532404.

Pasztor, E. M., Hollinger, D. S., Inkelas, M., & Halfon, N. (2006). Health and mental health services for children in foster care: The central role of foster parents. *Child Welfare: Journal of Policy, Practice, and Program, 85*(1), 33–57.

Raman, S., Reynolds, S., & Khan, R. (2011). Addressing the well-being of Aboriginal children in out-of-home care: Are we there yet? *Journal of Paediatrics and Child Health, 47*(11), 806–811. https://doi.org/10.1111/j.1440-1754.2011.02030.x.

Randsalu, L. L. L. (2018). Children in out-of-home care are at high risk of somatic, dental and mental ill health. *Acta Paediatrica, 107*(2), 301–306. https://doi.org/10.1111/apa.14108.

Royal Australasian College of Physicians (2006). *Health of children in "out-of-home" care.* Sydney: RACP.

Rubin, D., O'Reilly, A., Luan, X., & Localio, A. R. (2007). The impact of placement stability on behavioral well-being for children in foster care. *Pediatrics, 119*(2), 336–344.

Sawyer, M. G., Carbone, J. A., Searle, A. K., & Robinson, P. (2007). The mental health and wellbeing of children and adolescents in home-based foster care. *Medical Journal of Australia, 186*(4), 181–184.

Schneiderman, J. U. (2008). Qualitative study on the role of nurses as health case managers of children in foster care in California. *Journal of Pediatric Nursing, 23*(4), 241–249. https://doi.org/10.1016/j.pedn.2006.10.003.

Schneiderman, J. U., Smith, C., & Palinkas, L. A. (2012). The caregiver as gatekeeper for accessing health care for children in foster care: A qualitative study of kinship and unrelated caregivers. *Children and Youth Services Review, 34*(10), 2123–2130. https://doi.org/10.1016/j.childyouth.2012.07.009.

Tremellen, S., & Van Doorn, H. (2012). General practice: Role and experience as providers of comprehensive health assessment for children and young people in out-of-home care. *Developing Practice, 30*, 41–48.

Vimpani, G., Boland, K., Barr, M., & Marshall, J. (2012). Children in out-of-home care in NSW: What do their case files tell us about their health care? *Developing Practice, 30*, 53–62.

Withington, T., Burton, J., Lonne, B., & Eviers, A. (2016). Carer perspectives of factors affecting placement trajectories of children in out-of-home care. *Children and Youth Services Review, 65*, 42–50. https://doi.org/10.1016/j.childyouth.2016.03.006.

York, W., & Jones, J. (2017). Addressing the mental health needs of looked after children in foster care: The experiences of foster carers. *Journal of Psychiatric & Mental Health Nursing, 24*(2/3), 143–153. https://doi.org/10.1111/jpm.12362.

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ORIGINAL ARTICLE

Health needs and timeliness of assessment of Victorian children entering out-of-home care: An audit of a multidisciplinary assessment clinic

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Aim: To describe the health needs identified in children attending a comprehensive health assessment at a tertiary hospital, multidisciplinary clinic for children following entry to out-of-home care and timeliness of referral and assessment compared with national recommendations.

Methods: This was a retrospective audit of all the children who attended the Pathway to Good Health clinic at The Royal Children's Hospital, Melbourne from May 2013 until 31 August 2016.

Results: A total of 119 children aged 0–12 years attended the clinic during the audit period. Of these children, 17% (including more than 30% of 0–2-year-olds) were not up-to-date with immunisations, and 87% had physical health concerns that were addressed on the day or needed further management. Over 50% had mental health concerns identified (76% of 7–12-year-olds). In children aged 3–6 years, 64% had behavioural problems and 77% had developmental problems identified.

Only a third of the children was referred to the Pathway to Good Health clinic within the national standard of 30 days post-entry to care, and 24% of children attended within 3 months of entry to care.

Conclusion: Children in out-of-home care within Victoria have high rates of physical, mental and developmental health concerns, consistent with previous studies. Timeliness of attendance at the clinic was low compared with national recommendations, even within a programme designed to facilitate timely health checks. This is the second and largest Australian study exploring timeliness of health checks. Further research would establish whether these results are more systemic.

Key words: child; child health; foster care; health assessment; out-of-home care.

What is already known on this topic

1. Children in out-of-home care (OOHC) have high health needs across all domains of health.
2. The Australian National Standards for children and young people in OOHC and the National Clinical Assessment Framework recommend timely health assessment following entry to OOHC, including an initial check within 30 days and a comprehensive assessment within 3 months.
3. It is challenging to provide timely health assessments for this cohort.

What this paper adds

1. Victorian children in OOHC have high rates of health needs across all domains of health. The majority of children did not receive timely health checks that met national recommendations despite a dedicated clinic.
2. Immunisation rates for 0–2-year-old children in OOHC in Victoria were less than 70% despite several months in care.

Children living in out-of-home care (OOHC) are known to have higher rates of physical,[1–4] mental[5–9] and developmental[4,8,10] health needs than the general population. This is not surprising as the factors that have led to their placement in care are also those that are known to heighten vulnerability across all domains of health.[11,12] These high rates of problems have also been shown in a small number of Australian studies from New South Wales,[13–17] South Australia[18] and Queensland.[19,20] However, there are minimal Victorian data, with only two small older studies reporting either mental health problems (2002) from a screening clinic ($n = 131$)[21] or physical health problems and referrals made ($n = 24$) in a pilot general practice (GP) programme (2008).[22]

This high morbidity load is of increasing concern as the number of children and young people living in OOHC in Victoria and Australia has been steadily rising. In Victoria alone, the number

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and prevalence of children and young people in OOHC has increased by 50% from 6207 (5.0 per 1000) in 2012 to 10 312 (7.5 per 1000) in 2017. In 2017, there were 47 915 children and young people in Australia living in OOHC (8.7 per 1000 children aged 0–17 years).[23]

When children are removed from birth families, the relevant authorities take on (directly or through delegation) the responsibility for the identification and management of their health needs. However, case managers and carers are often not well placed to accurately identify health needs.[20]

In recognition of the high health needs and the limitations of case managers and carers identifying and addressing these needs,[20] peak bodies, including the American Academy of Pediatrics[24] and the Royal Australasian College of Physicians,[25] have recommended routine, timely, systematic screening of health needs at entry to care (and regularly thereafter). Such screening is a statutory requirement in the UK[26] but not in Australia, where OOHC is managed separately by each state and territory. Australia does have National Standards for OOHC[27] and the National Clinical Assessment Framework for children in OOHC,[28] both from federal government departments. These stipulate routine, timely and comprehensive health assessments, including an initial health check within primary care by 30 days following entry to OOHC, routine optometry, dental and audiology assessments and a comprehensive health assessment by 3 months following entry to OOHC.

Despite the importance of timeliness in the early identification of needs, there are few studies that report on timeliness. Some North American studies have shown that timeliness is challenging[29,30] but can be improved by addressing funding issues[31] or implementing dedicated service delivery models[32,33] To our knowledge, only one Australian study reports on timeliness of assessment in a small pilot of 24 children.[22]

Victoria has no state-wide approach to identifying and managing the health needs of children in OOHC. Following the release of the National Clinical Assessment Framework in 2011, the Pathway to Good Health (PTGH) programme was established, initially in north and west metropolitan Melbourne in 2013 and then expanding regionally in 2015. This programme identified general practitioners who were willing and able to provide initial assessments within 4 weeks of entry to OOHC, recommended routine optometry and dental visits within 3 months and established dedicated multidisciplinary clinics for comprehensive health and developmental assessments around 3 months following entry to OOHC. The clinic at the Royal Children's Hospital (RCH), Melbourne, is one of three metropolitan multidisciplinary clinics. This study aimed to describe the health needs of the children seen in the PTGH multidisciplinary clinic at RCH and compare the timeliness of their comprehensive health assessment and GP visit with national recommendations.

Methods

Setting

This study is a retrospective audit of the health notes and Health Management Plans for the first consecutive 119 patients to attend the PTGH clinic at RCH from its commencement in May 2013 until 31 August 2016. The PTGH Clinic at RCH is funded by the Victorian Department of Health and Human Services to provide comprehensive health assessments for children aged 0–12 years following entry to OOHC in the north or west metropolitan Melbourne area. The Child Protection case manager initiates the process by facilitating a GP visit, and referral is then made to the clinic.

The child attends the clinic once, accompanied by one or more of the following adults: his or her foster or kinship carer, departmental case manager or case worker from a foster care agency. Other attendees may include other foster family members, siblings in the same placement as the child, biological parents or other birth family members. Children are assessed by a paediatrician and a psychologist, and those aged from 2 to 7 years (inclusive) are also assessed by a speech pathologist. The clinicians take 2–3 h to assess the child, including taking a standardised history from the child and any accompanying adults (using a checklist), observation of the child and physical examination. The speech and language assessment may include standardised tests. A single health management plan is co-written by the clinicians and sent to the case manager, referring GP and health professionals caring for the child. This plan outlines identified health needs and recommended next steps for treatment or further assessment.

Data collection and analysis

The authors entered de-identified data included demographic information (age, gender, placement information (where possible), date of entry to OOHC and previous episodes of OOHC). If the full date of entry was not available, a conservative estimate was used (e.g. if only a month and year were recorded, the last date of the month was used). To validate the accuracy of the data entry, the authors independently entered data for 10% of the cohort. Where agreement between researchers was less than 90% for any variable, both researchers jointly reviewed all patients.

Physical health problems and concerns about development, behaviour (e.g. aggressive, difficult to manage or unusual behaviours), schooling or mental health (e.g. abnormal attachment, trauma-related symptoms) were noted if they required either attention during the assessment or a recommendation in the health management plan. Recommendations and referrals were recorded, and if they had already been initiated by someone else, this was also noted.

Descriptive statistics were calculated using Stata (Stata v15.1, released 2017, College Station, TX, USA).

Ethical approval for the audit was granted by the RCH Human Research Ethics Committee (36258A).

Results

A total of 119 children were seen during the study period. Demographics of the cohort are shown in Table 1. While two thirds of the cohort were in their first placement, more than 20% had changed placement at least once. The median time to GP referral from entry to OOHC was 57 days (ranging from 1 to 2359 days); it was shorter for 0–2-year-old children (48 days) than 7–12-year-old children (88 days). The median time from GP referral to clinic visit was 70 days. Overall, the median time from entry to OOHC to comprehensive health assessment in the clinic

Table 1 Demographics of study sample

Total	*n* (%)
Gender	
Male	58 (48.7)
Female	61 (51.3)
Age, years	
<1	9 (7.6)
1–2	26 (21.8)
3–6	39 (32.8)
7–12	45 (37.8)
Aboriginal and/or Torres Strait Islander children	17 (14.3)
Care type	
Foster care	43 (36.1)
Kinship care	69 (58.0)
Residential care	1 (0.8)
Other†	6 (5.0)
Number of placements	
0	2 (1.7)
1	79 (66.4)
2	16 (13.5)
3	3 (2.5)
4 or more	6 (5.0)
Unknown	13 (10.9)

†Other included reunified, never in out-of-home care (brought as a sibling) and other care arrangement.

was 163 days (range 35–2472 days), varying from a median of 117 days for the 0–2-year-old children to 212 days for the 7–12-year-old children. Table 2 shows the proportion meeting the national recommendations for timeliness of visits.

Figure 1 shows the proportion of children who had dental, hearing or vision assessments before attending the clinic. The highest rates of assessments were dental reviews in children aged 7–12 years, where over half of the children had already seen the dentist.

Table 3 shows the immunisation status at the time of the clinic visit. For some children, this was not evident, and these were classified as 'not known'. Over 30% of 0–2-year-old children who attended were not up-to-date with their immunisations as per the National Immunisation Schedule.

Figure 2 shows the proportion identified with health concerns in each domain of health within each age group and the entire cohort. Only 13% of children had no physical health problems discussed or identified in their assessment. Many physical health concerns were typical of childhood health problems: 16 children (14%) had asthma, and 29 (24%) had eczema. Abdominal pain, constipation and/or encopresis were found in 29 children (24%). Sleep problems, including symptoms of obstructive sleep apnoea, parasomnias and behavioural sleep challenges, were found in 17 children (14%). Seven children (6%) were found to have previously unidentified heart murmurs, and three were found to have previously attended our hospital for follow-up of cardiac or renal abnormalities and then failed to attend ongoing follow-up, unknown by either carers or case managers.

Mental health concerns were identified in the majority of children aged over 3 years and up to 76% of 7–12-year-old children.

Table 2 Comparison with the National Clinical Assessment Framework

Recommendation	Age, years	Meeting recommendation, *n* (%)
GP visit by 30 days generating referral to PTGH clinic	0–2	10 (28.5)
	3–6	15 (38.5)
	7–12	14 (31.1)
	All	39 (32.8)
PTGH comprehensive assessment by 3 months (92 days)	0–2	12 (34.2)
	3–6	10 (25.6)
	7–12	6 (13.3)
	All	28 (23.5)

GP, general practitioner; PTGH, Pathway to Good Health.

These often related to experiences of trauma and internalising symptoms being identified. Almost half of all children had challenging behaviours in either the home or school setting, from excessive tantrums to aggression. Developmental concerns were most prevalent in the 3–6-year-old age group; speech and language concerns were the most frequently identified. Two thirds of children aged 7–12 years old had school-related concerns, usually academic and/or peer related.

Table 4 reports the frequency of new recommendations made in health management plans at the end of assessment; other treatment or referrals that had already been initiated were not included. Around half of all children were found to need ongoing paediatric care because of the nature and/or extent of concerns. Twenty-one children (18%) were referred to another medical or surgical specialist specifically as a result of their clinic attendance. Close to half of all children had recommendations relating to their mental health (for further assessment and/or therapy), including 77% of 7–12-year-old children. Over half of 3–6-year-old children needed an audiology assessment, which often followed identification of speech and language concerns in children who had not yet had their hearing tested; 62% of this age group had speech therapy recommended.

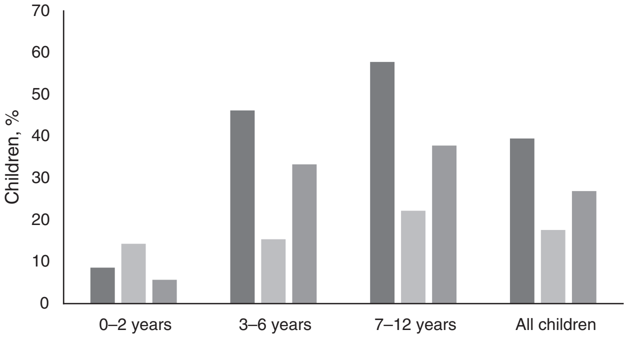

Fig. 1 Proportion of children who had completed dental, hearing and vision assessments before attending clinic. (■), Dentist; (□), audiology; (▨), vision.

Table 3 Immunisation status at time of clinic visit

Immunisation status	0–2 years, *n* (%)	3–6 years, *n* (%)	7–12 years, *n* (%)	Total, *n* (%)
Up-to-date	22 (62.9)	32 (82.1)	34 (75.6)	88 (74.9)
Not up-to-date	11 (31.4)	5 (12.8)	4 (8.9)	20 (16.8)
Unknown	2 (5.7)	2 (5.1)	7 (15.6)	11 (9.2)

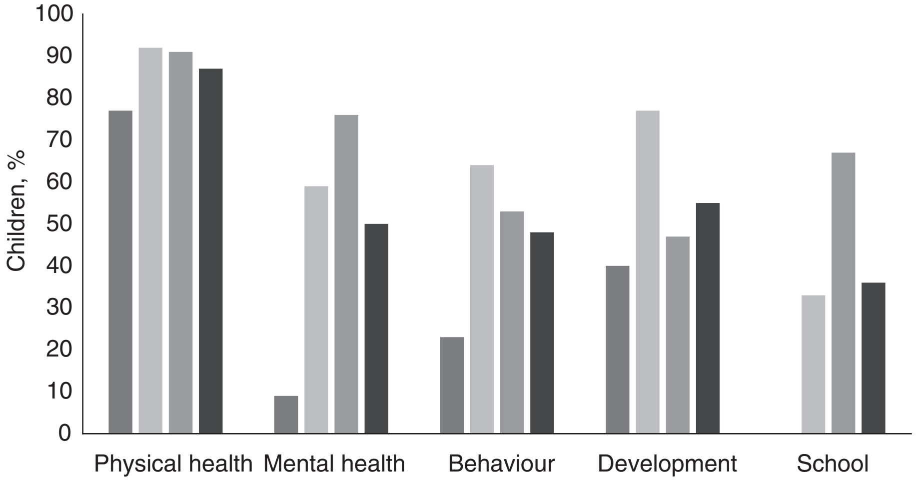

Fig. 2 Percentage of children with concerns by age and health domain. (■), 0–2-year-old children; (■), 3–6-year-old children; (■), 7–12-year-old children; (■), total cohort.

Table 4 Recommendations made after clinic assessment

Recommendation	0–2-year-olds, *n* (%)	3–6-year-olds, *n* (%)	7–12-year-olds, *n* (%)	Total, *n* (%)
Referral to paediatrician	11 (31.4)	19 (54.3)	24 (53.3)	54 (45.4)
Other new subspecialty referral	8 (22.9)	7 (17.9)	6 (13.3)	21 (17.6)
Dentist	4 (11.4)	13 (33.3)	17 (37.8)	34 (28.6)
Audiology	11 (31.4)	21 (53.8)	14 (31.1)	46 (38.7)
Vision	5 (14.3)	12 (30.8)	15 (33.3)	32 (26.9)
Mental health referral	3 (8.6)	20 (51.3)	32 (71.1)	55 (46.2)
Speech therapy	4 (11.4)	18 (46.2)	8 (17.3)	30 (25.2)

Discussion

This study describes the health needs identified at a comprehensive multidisciplinary assessment clinic for Victorian children in OOHC. Health needs and recommendations for further health service use were highly prevalent across all domains of health, consistent with previous interstate and international studies. The timeliness of attendance at the clinic was poor when compared to national recommendations.

Physical health needs were the most prevalent. While some health problems appear to be comparable with parent-reported rates for all Australian children (e.g. asthma, sleep problems),[34] others were more prevalent among the study cohort than Australian children,[34] although possibly in line with some global general prevalence rates (e.g. eczema, abdominal pain, constipation and soiling).[35] The overall high prevalence of physical health problems is in line with other Australian studies of children in OOHC.[14,19,20] Some of the somatic symptoms identified in the clinic may have had an underlying mental health aetiology, in line with previous studies that have shown increased somatic symptoms in children with exposure to trauma.[36]

While routine dental, vision and audiology (hearing) checks are included in the national guidelines, audiology was not included in the PTGH programme as a routine requirement. It is therefore unsurprising that fewer children had audiology compared with dental and vision checks before attending the clinic. However, it is concerning that only 52% of children aged at least 3 years had attended a dentist, especially when considering the poor timeliness in attendance.

It was also concerning that immunisation rates were low despite the comprehensive health assessment following at least one contact with the primary health-care system for an initial health check. This was true particularly among the 0–2-year-old children, where at best 69% were fully immunised as per the National Immunisation Schedule by the time of their clinic appointment – despite 66% having been in OOHC for more than 3 months.

While physical health problems were most prevalent, mental health, developmental and behavioural concerns were also prevalent. These domains of health are known to contribute to placement breakdown for children in OOHC,[37–40] and placement breakdown appears to impede the provision of health care.[41] At least 20% of our cohort had changed placement at least once prior to their comprehensive health assessment, but total numbers were too small to explore the relationship between mental health concerns, placement breakdown and timeliness of assessment.

It is unsurprising that mental health and developmental concerns generated the most recommendations for further assessment or treatment. The high rates of referral for mental health care, speech therapy and ongoing paediatric care are also similar to interstate Australian studies[14,15,19,20,22] and add to the evidence that children in OOHC warrant both careful and timely identification of health needs and access to services.

Based on models elsewhere that have been shown to facilitate health checks,[32,33] the PTGH programme was designed to facilitate timely health assessments for children following entry to OOHC. This audit shows that an initial health check by 1 month may have only been achieved in about one third of children, and a comprehensive health check by 3 months was completed in about one quarter. However, it is not clear whether the GP visit that generated the referral was the first GP visit for these children; it is possible that more children had a prompt initial health check and were then referred to the clinic on a subsequent visit. However, the low figures for timely comprehensive health checks suggest that timeliness of identification of health needs of children entering OOHC is poor.

Despite data from only one clinic, this study is the largest Victorian and one of the largest Australian studies of health needs in children in OOHC across all domains of health.[40,41] This is also the second and largest Australian study to report on the timeliness of attendance in a model designed to provide timely assessment of health needs upon entry to OOHC.

There are considerable limitations to this study worth noting. The sample in this cohort is limited to those referred for a comprehensive health assessment in one PTGH clinic. Our sample is broadly similar to children in OOHC in Victoria, with 49% boys and 58% in kinship care compared to 52 and 49% of Victorian children in OOHC in 2016–2017, respectively.[23] However, only 14% of our cohort were Aboriginal and/or Torres Strait Islander children (compared to 20% of Victorian children in OOHC).

The findings regarding timeliness are limited by the lack of information about GP visits and initial health assessments outside of the visit that generated the referral to our clinic. The generalisability of our findings is limited by the absence of information about children who were not referred to the clinic. We cannot determine from this study the overall rates and timeliness of health checks within Victoria or be confident about whether the sample seen in the clinic was representative of all children in OOHC with respect to health needs. Further research is needed to determine the true timeliness of health assessment for all children in OOHC and to explore barriers and enablers to health service access.

Conclusion

Children in OOHC within Victoria had high rates of physical, mental and developmental health concerns, adding to previous Australian and international research. Immunisation rates were low, particularly for the youngest children (aged 0–2 years). Timeliness of attendance at the dedicated multidisciplinary assessment clinic for a comprehensive assessment of health needs was poor compared with national recommendations, even within a broader programme designed to facilitate timely health checks. Timely identification and management of health needs for children in OOHC continue to be challenging to deliver.

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References

1 Deutsch SA, Fortin K. Physical health problems and barriers to optimal health care among children in foster care.*Curr. Probl. Pediatr. Adolesc. Health Care* 2015; **45**: 286–91.

2 Dubowitz H, Feigelman S, Zuravin S, Tepper V, Davidson N, Lichenstein R. The physical health of children in kinship care.*Am. J. Dis. Child.* 1992; **146**: 603–10.

3 Flaherty EG, Weiss H. Medical evaluation of abused and neglected children.*Am. J. Dis. Child.* 1990; **144**: 330–4.

4 Leslie LK, Gordon JN, Meneken L, Premji K, Michelmore KL, Ganger W. The physical, developmental, and mental health needs of young children in child welfare by initial placement type.*J. Dev. Behav. Pediatr.* 2005; **26**: 177–85.

5 Teggart T, Menary J. An investigation of the mental health needs of children looked after by Craigavon and Banbridge health and social services trust.*Child Care Pract.* 2005; **11**: 39–49.

6 Williams J, Jackson S, Maddocks A, Cheung W, Love A, Hutchings H. Case-control study of the health of those looked after by local authorities.*Arch. Dis. Child.* 2001; **85**: 280–5.

7 Egelund T, Lausten M. Prevalence of mental health problems among children placed in out-of-home care in Denmark.*Child Fam. Soc. Work* 2009; **14**: 156–65.

8 Deutsch SA, Lynch A, Zlotnik S, Matone M, Kreider A, Noonan K. Mental health, behavioral and developmental issues for youth in foster care.*Curr. Probl. Pediatr. Adolesc. Health Care* 2015; **45**: 292–7.

9 Conn A-M, Szilagyi MA, Alpert-Gillis L, Baldwin CD, Jee SH. Mental health problems that mediate treatment utilization among children in foster care.*J. Child Fam. Stud.* 2016; **25**: 969–78.

10 Ford T, Vostanis P, Meltzer H, Goodman R. Psychiatric disorder among British children looked after by local authorities: Comparison with children living in private households.*Br. J. Psychiatry* 2007; **190**: 319–25.

11 Marmot M. Social determinants of health inequalities.*Lancet* 2005; **365**: 1099–104.

12 Felitti VJ, Anda RF, Nordenberg D *et al.* Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study.*Am. J. Prev. Med.* 1998; **14**: 245–58.

13 Chambers MF, Saunders AM, New BD, Williams CL, Stachurska A. Assessment of children coming into care: Processes, pitfalls and partnerships.*Clin. Child Psychol. Psychiatry* 2010; **15**: 511–27.

14 Nathanson D, Tzioumi D. Health needs of Australian children living in out-of-home care.*J. Paediatr. Child Health* 2007; **43**: 695–9.

15 Raman S, Reynolds S, Khan R. Addressing the well-being of aboriginal children in out-of-home care: Are we there yet?*J. Paediatr. Child Health* 2011; **47**: 806–11.

16 Raman S, Sahu S. Health, developmental and support needs of vulnerable children – Comparing children in foster care and children in need.*Child Abuse Rev.* 2014; **23**: 415–25.

17 Tarren-Sweeney M, Hazell P. Mental health of children in foster and kinship care in New South Wales, Australia.*J. Paediatr. Child Health* 2006; **42**: 89–97.

18 Sawyer MG, Carbone JA, Searle AK, Robinson P. The mental health and wellbeing of children and adolescents in home-based foster care. *Med. J. Aust.* 2007; **186**: 181–4.

19 Arora N, Kaltner M, Williams J. Health needs of regional Australian children in out-of-home care.*J. Paediatr. Child Health* 2014; **50**: 782–6.

20 Kaltner M, Rissel K. Health of Australian children in out-of-home care: Needs and carer recognition.*J. Paediatr. Child Health* 2011; **47**: 122–6.

21 Milburn NL, Lynch M, Jackson J. Early identification of mental health needs for children in care: A therapeutic assessment programme for statutory clients of child protection.*Clin. Child Psychol. Psychiatry* 2008; **13**: 31–47.

22 Tremellen S, Van Doorn H. General practice: role and experience as providers of comprehensive health assessment for children and young people in out-of-home care.*Dev. Pract.* 2012; **30**: 41–8.

23 Australian Institute of Health and Welfare. *Child Protection Australia 2016–17*. Canberra: The Institute; 2018.

24 Canadian Paediatric Society. Special considerations for the health supervision of children and youth in foster care.*Paediatr. Child Health* 2008; **13**: 129–36.

25 Royal Australasian College of Physicians. *Health of Children in "Out-of-Home" Care*. Sydney: The College; 2006.

26 Department for Education and Department of Health. *Promoting the Health and Well-Being of Looked-after Children: Statutory Guidance for Local Authorities, Clinical Commissioning Groups and NHS England.* London: The Department; 2015.

27 Department of Families Housing, Community Services and Indigenous Affairs together with the National Framework Implementation Working Group. *An Outline of National Standards for Out-of-Home Care.* Canberra: Department of Social Services; 2011.

28 Child Health and Wellbeing Subcommittee, Australian Population Health Developmental Principal Committee. *National Clinical Assessment Framework for Children and Young People in Out-of-Home Care (OOHC)*. Canberra: Department of Health; 2011.

29 Goldade R, Tortorelli C. P-KIC -pediatrics for kids in care.*Paediatr. Child Health* 2010; **15**: 10A.

30 Knight EK, McDuffie MJ, Gifford K, Zorc C. Health service utilization of children in Delaware foster care, 2013–2014.*Del. Med. J.* 2016; **88**: 46–52.

31 Day A, Curtis A, Paul R, Allotey PA, Crosby S. Timely health service utilization of older foster youth by insurance type.*J. Adolesc. Health* 2016; **58**: 17–23.

32 Risley-Curtiss C, Stites B. Improving healthcare for children entering foster care.*Child Welfare* 2007; **86**: 123–44.

33 Jee S, Szilagyi M, Blatt S, Meguid V, Auinger P, Szilagyi P. Timely identification of mental health problems in two foster care medical homes.*Child. Youth Serv. Rev.* 2010; **32**: 685–90.

34 Liu T, Lingam R, Lycett K *et al.* Parent-reported prevalence and persistence of 19 common child health conditions.*Arch. Dis. Child.* 2018; **108**: 548–56.

35 Waterham M, Kaufman J, Gibb S. Childhood constipation.*Aust. Fam. Physician* 2017; **46**: 908–12.

36 Kugler BB, Bloom M, Kaercher LB, Truax TV, Storch EA. Somatic symptoms in traumatized children and adolescents.*Child Psychiatry Hum. Dev.* 2012; **43**: 661–73.

37 Park JM, Ryan JP. Placement and permanency outcomes for children in out-of-home care by prior inpatient mental health treatment.*Res. Soc. Work Pract*. 2009; **19**: 42–51.

38 Sallnas M, Vinnerljung B, Westermark PK. Breakdown of teenage placements in Swedish foster and residential care.*Child Fam. Soc. Work* 2004; **9**: 141–52.

39 Brown JD, Bednar LM. Foster parent perceptions of placement breakdown.*Child. Youth Serv. Rev.* 2006; **28**: 1497–511.

40 Koh E, Rolock N, Cross TP, Eblen-Manning J. What explains instability in foster care? Comparison of a matched sample of children with stable and unstable placements.*Child. Youth Serv. Rev.* 2014; **37**: 36–45.

41 Kerns SEU, Pullmann MD, Putnam B *et al.* Child welfare and mental health: Facilitators of and barriers to connecting children and youths in out-of-home care with effective mental health treatment.*Child. Youth Serv. Rev.* 2014; **46**: 315–24.