

Research Article

Integrating Parents of Children with Special Health Care Needs into the Pediatric Medical Home

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Abstract

The medical home is an approach to providing comprehensive and coordinated care to children and families, including those impacted by special health care needs (CSHCN); it supports families with both medical and non-medical needs. Connecting families to non-medical community support services is challenging for many clinical providers. The Parent Partner Program was designed to train parents of CSHCN to work in their community pediatricians' practices and help other families of CSHCN navigate clinical and social support services. The Parent Partner Program was implemented in eight pediatric primary care clinics across Montana and Wyoming in 2012. Three surveys were implemented to investigate the perceptions of participating providers, Parent Partners, and parents. The surveys indicated medium to high levels of satisfaction with the Parent Partner Program among all stakeholder groups. Despite limited perceived family awareness, the program has shown early successes in providing emotional support for families and improving practice efficiency. Areas for improvement included adding more in-depth training on topics and improving ongoing communication between care team members. Community-based pediatricians may consider implementing a patient navigation model such as the Parent Partner Program as an approach to providing more comprehensive care to families of CSHCN.

ABBREVIATIONS

CSHCN: Children with Special Health Care Needs; MSGRC: Mountain States Genetics Regional Collaborative; HIPAA: Health Insurance Portability and Accountability Act; CHIP: Children's Health Insurance Program

INTRODUCTION

The medical home was originally described in the context of children with special health care needs (CSHCN) in the 1960s and outlined an approach to keeping information about the child in a centralized location [1]. Since then, the medical home model has evolved to include the broader population of children, but with a general focus on those with complex health needs. In its most recent iteration, the medical home is described as including care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective [2]. The intensive focus on the medical home in recent years has led to substantial public and private investments in identifying measures of outcomes within the medical home and certifying clinical practices that meet standards. As the medical home concept has evolved, so have community- and practice-based efforts to meet its expectations.

Families of CSHCN face barriers to gaining adequate care for their children. According to the 2009/2010 National Survey of Children with Special Health Care Needs, just under 10 percent of children had at least one period without health insurance coverage in the previous year [3]. While the rates of insurance coverage were higher than for the general population, 34 percent of those with insurance reported that it was inadequate [3]. Just over seven percent of families reported at least one unmet need for family support services such as respite care and mental health care [3]. This may indicate that families could benefit from programs that facilitate access to these services. Almost 35 percent of families had difficulties or delays in receiving community based services including early intervention and special education, and over 35 percent expressed frustration with getting their child services [3]. While pediatricians are more than adequately prepared to serve (or make referrals for) a patient's medical needs, they are unlikely to have experience with or training in accessing non-medical services many CSHCN families need. To that end, parents of CSHCN who have on-the-ground experience in navigating local health care and social service delivery systems may generate benefits for CSHCN families served in the community-based pediatric clinical setting.

Community providers also face challenges in serving families of CSHCN. In their survey of primary care physicians serving families of CSHCN, Davidson (2002), et al., found that physicians reported at least some level of dissatisfaction with their patients' access to mental health care, information for families, and care coordination services [4]. The survey also revealed that primary care physicians desired more time and resources, including staff, to adequately serve CSHCN families [4]. Community-based pediatricians may face added stressors when unable to deliver comprehensive services, especially non-medical social support services, to CSHCN families. Physicians that experience burnout can have lower levels of productivity [5], and practice workload is a frequent contributor to increased levels of burnout [6].

Typically, CSHCN have complex needs requiring multiple subspecialty providers. The primary care provider, who is likely the community-based pediatrician for CSHCN, maintains responsibility for serving as the medical home. In a Montana-based survey, Hardy (2013), et al., found that availability of pediatric specialty providers and communication between primary care and specialty care providers were barriers to effectively treating CSHCN [7]. Comprehensive systems of care, including one facilitated by the medical home, require adequate and effective communication across all providers and with the family [8]. High levels of communication are not always achieved but have been shown to improve with intervention [9,10]. Strategic communication among the care team and between the care team and family can facilitate shared decision making. Shared decision making with families of CSHCN has been shown to lower rates of hospitalizations and emergency room visits, and may even reduce overall health care costs [11].

MATERIALS AND METHODS

In response to the challenges highlighted above, efforts to engage parents as navigators in the medical home have held promise for assisting other parents of CSHCN with getting their children necessary care and services. The Hali Project, a not-for-profit organization based in Canyon, Texas, developed one such program. The Hali Project Parent Partner Program works with community-based pediatric primary care practices to identify, train, and support parents of children with complex conditions to serve as navigators for other families facing similar challenges. Identification of Parent Partners begins in the pediatric clinic. Pediatricians are recruited to participate in the program and agree to identify at least one parent of a child with CSHCN within their practice to serve as a Parent Partner.

The training preparing Parent Partners for this project was led by the Executive Director of the Hali Project, who started the program in the office of the pediatrician caring for his child with special needs. The Parent Partner training prepared trainees to connect families to resources, and to serve as a person on whom families could rely as they navigated the system of care for their child. The training included modules on skill development in the areas of compiling information about local, credible services for families of CSHCN; identifying needs of CSHCN patients and families; communicating needs to the clinical care team; serving as liaison between the clinic, family, and community; and communicating with families to assist with navigating systems of care. Additionally, the training included information on the

emotional process that accompanies a CSHCN diagnosis and methods for determining where a parent might be in that process. This final piece was included to facilitate the Parent Partner's ability to help caregivers find acceptance of their situation, then work to create the best possible life for their children.

The initial in-person training was supplemented by routine peer-to-peer support via teleconference. A notable difference between the Parent Partner Program and other navigator programs was the trainer's emphasis on regularly evaluating each Parent Partner for his/her current state of emotional health and ability to function in the Parent Partner role. The ongoing peer-to-peer support phone calls allowed for assessment of the Parent Partner's progress not only in fulfilling his/her responsibilities under the Parent Partner Program, but also in balancing her personal needs with those professional responsibilities.

Trained Parent Partners were charged with building relationships with other families of CSHCN within their local pediatric clinic and helping those families gain access to needed medical and social services for their children. Parent Partners worked within the pediatric clinic in which they were hired. Families were invited to participate in the program by the clinical team. Parent Partners provided in person assistance and support via phone calls. The frequency and duration of the interactions between the Parent Partners and families depended on family needs. This model was described by participants as giving the Parent Partners the role of meeting the non-medical care aspects of the medical home.

From 2012-2015, the Mountain States Genetics Regional Collaborative (MSGRC) provided program and evaluation support for implementation of the Hali Project Parent Partner Program in eight pediatric practices across Montana and Wyoming. These two states were targeted given their rural nature and willingness to proceed with pilot programs to improve services to families of CSHCN. Pediatric practices actively involved in or peripherally engaged with the MSGRC were invited to participate in the program. Each participating practice recruited Parent Partners for the training. The initial Parent Partner Program evaluation was primarily process-driven, assessing process and implementation outcomes. The evaluation included several aims measuring: 1). The extent to which the program was institutionalized within the pediatric practice; 2). The fidelity of the program to the original Hali Project training curriculum; and 3). The outcomes of the program from the perspective of three primary stakeholder groups – Parent Partners, providers, and families served. This paper describes findings related to Aim 3, through which program outcomes were measured.

The three stakeholder groups had separate roles in the Parent Partner Program and were expected to have input on different theoretical constructs of the program. Three separate surveys were developed for the purpose of evaluation (in consultation with the Parent Partner Program Director) to assess perceptions from each stakeholder group. The provider survey sought to measure satisfaction, practice implementation, and the impact on their clinical practice. One specific outcome of interest with regard to clinic practice outcomes was the difference in time spent with patients when a Parent Partner was present. Providers reported the average time spent during a visit with a child with special

health care needs as: more than thirty minutes; between twenty to less than thirty minutes; ten to less than twenty minutes, and less than ten minutes. This question was asked separately for visits with and without the Parent Partner present.

Table 1 outlines the constructs measured, the targeted stakeholder group, and examples of survey questions included. Responses were collected using a Likert scale for each survey question; for example, 1=strongly disagree and 6=strongly agree. Provider survey questions also included five ordinal-scaled questions measuring: duration of time working with Parent Partners; number of CSHCN provided care in a typical week; frequency that Parent Partners were present during patient visit; and amount of time spent during patient visit for CSHCN patient in presence, and in absence, of Parent Partner in the room.

The sampling frame for the Parent Partner survey included all practicing Parent Partners in Montana and Wyoming (n=7). The sampling frame for the provider survey included pediatricians at each participating clinic (n=12). The sampling frame for the parent survey included all parents reported to have been served by a Parent Partner within those clinics (originally estimated at n~100). The study was approved as exempt by the Institutional Review Board at the University of North Texas Health Science Center.

The provider and Parent Partner surveys were disseminated electronically via email invitations. Responses to each were collected in the fall of 2013, approximately one year into the program. An initial parent survey was disseminated in 2013 but responses were limited and the evaluation team determined a need for expanding the reach of the survey by allowing more time for patients to initiate participation in the program. In early 2015, an expanded parent survey was disseminated to families by the Parent Partners within each participating clinic via paper surveys. Paper parent survey responses were mailed directly to the program evaluator via a prepaid envelope and were entered manually into a spreadsheet for analysis by members of the evaluation team.

The response rates were as follows: 100% for Parent Partner survey and 25% for provider survey. The response rate for the parent survey is unknown since dissemination was conducted by clinic staff. Survey responses were analyzed for descriptive statistics and, where possible, tests of comparisons were used. Mean scores and standard deviations for Likert-scaled questions related to each measured construct are reported. Statistically significant differences in provider-reported visit time when a Parent Partner was present, versus when the Parent Partner was absent, were analyzed using a one-tailed paired t-test. Iterative, thematic qualitative analysis was used to analyze written, non-numeric survey responses. Using this approach, content themes were coded within the data and validated by a member not involved in the initial coding.

RESULTS

Parent partner survey

Parent Partners reported high mean levels of agreement with both the clarity of training objectives, and the relevance of the training topics to their day-to-day responsibilities in the practice.

Clarity of training objectives included two items measuring the clarity of training objectives at the start of the training (mean score of 5.2 out of 6; SD=0.49) and the extent to which the objectives were met at the end of the training (mean score of 5.14 out of 6; SD=0.69). Relevance of the training topics included three survey items measuring relevance to daily duties, organization of training materials, and usefulness of training to daily work (each item had a mean score of 5.14 out of 6; SD=0.69). Parent Partners also reported high mean levels of agreement with the interaction between the trainer and trainees (5.4 out of 6; SD=0.53) and indicated that the duration of the training program was suitable for the content, as measured by asking if the training was too long (mean score of 2.1 out of 6; SD=1.35) or too short (mean score of 2.8 out of 6; SD=1.07).

Parent Partners reported serving a mean of 25 families per month across all participating pediatric practices. Despite working with a number of families, Parent Partners indicated a potentially low level of parent awareness about the availability of the Parent Partner Program (only 3 of 7 Parent Partners reported that parents of CSHCN were aware of the program).

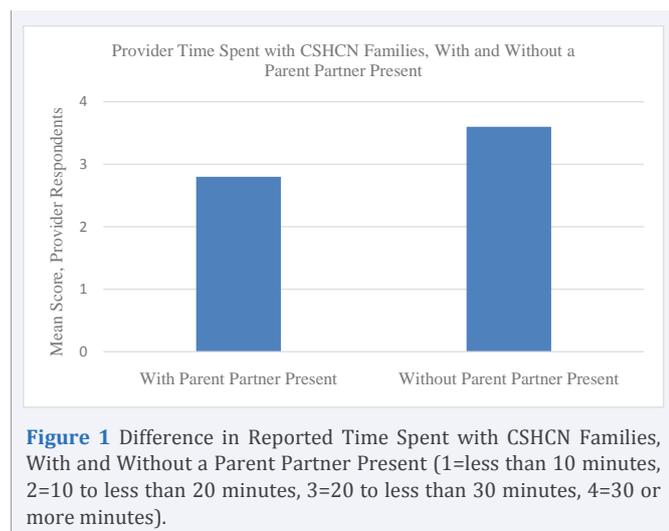
Five of the 7 respondents agreed that participating families were satisfied with their Parent Partner, and there was agreement (mean score of 5.3 out of 6; SD=0.76) that Parent Partners had timely responses to client needs. Parent Partners expressed mixed perceptions of whether there were adequate resources available to support the program functions within the practice setting. However, the average scores for survey questions related to this construct were between 4.1 and 4.7 out of six, indicating that most respondents were positive about the availability of resources.

Parent Partners made several recommendations for improving the program. Regarding the training, they suggested potentially longer and more frequent training sessions. In addition, they expressed interest in more focus on telephone communication with families and agencies that may serve families, more detail about how HIPAA rules impact their work, and suggestions on how to work with families of low socioeconomic status or with families affected by addiction. Finally, Parent Partners suggested that a stronger partnership with the clinical team (e.g. physicians and nurse coordinators) would be useful and may be facilitated by routine monthly meetings.

Provider survey

At the time of the survey, providers reported working with Parent Partners for at least one month and indicated that they saw, on average, somewhere between three to five CSHCN patients per week. According to providers, Parent Partners were not always present during CSHCN patient visits.

Overall, providers expressed satisfaction with the Parent Partner Program, indicating that they would recommend the program to other clinics serving children with special health care needs (mean score of 5.3 out of 6; SD=1.15). Providers reported a statistically significant difference in the time spent during the patient visit when the Parent Partner was present (p-value=0.03, Figure 1). Among the three physician respondents, one reported spending an average of 30 or more minutes with a CSHCN family when no Parent Partner was present, but only spending an



average of 20-30 minutes when a Parent Partner was present. The other two providers each reported spending 20-30 minutes with CSHCN families in the absence of a Parent Partner and either 10-20 or less than 10 minutes when a Parent Partner was present. One provider noted, "My practice has been greatly enhanced by the Parent Partners program. The patients and their families are given knowledge and empowered by the Parent Partner. This has improved quality of life for them. It has also made me more efficient allowing me to care for more children with special health care needs. It is a win-win situation". These preliminary findings indicate that quality may not be compromised, even when physicians spend less time on average with CSHCN families; in fact, quality may be enhanced.

The survey revealed a low score (mean score of 3.3 out of 6; SD=2.52) when providers were asked if families of CSHCN were promptly introduced to their Parent Partner after the first visit. This could be related to the availability of Parent Partners in-person within the clinic. One provider stated, "Our Parent Partners are in the office on a very limited basis. This makes it difficult for them to meet directly with the families". Although the provider went on to note the success of telephone follow-up, limited in-person availability may delay introduction to the Parent Partners.

Finally, one provider suggested that the addition of Parent Partners into their practice had revealed challenges families had in following the physician's clinical recommendations, and that the Parent Partners were able to help families resolve issues. Parent Partners "found out about things that the parent did not bring up with me that was a barrier to following my recommendations and found services to help the family."

Parent survey

Respondents to the parent survey (n=99, including some incomplete survey responses), were primarily female (88%) and White (91%). English was the primary language spoken at home for all but one respondent. Fifty two percent (52%) of respondents reported having at least some college as their highest level of education, and 55% were employed. Almost three quarters (71%) reported that their child's primary insurer was

Medicaid or CHIP. Table 2 includes demographic characteristics of all parent survey respondents.

Approximately 20% of respondents reported that their child had visited an emergency department within the previous three months. Twenty seven percent (27%) reported they had missed at least one medical appointment and 36% reported missing a therapy appointment within the previous three months. When offered a list of potential barriers to care, parents reported difficulty scheduling appointments (30.6% of question respondents), uncertainty of care needed (28.6%), inability to get time off work (24.5%), lack of child care (22.5%), lack of transportation (20.4%), inadequate insurance coverage (18.4%), and lack of available providers (14.3%) as barriers faced by their family.

Regarding the Parent Partner Program, parents expressed medium (28%) to high/very high (62%) levels of enthusiasm for the program, and no barriers to participating in the program (94%). Parents agreed or strongly agreed that they were able to identify (almost 58%) and access (70%) community resources after participation in the program. Over 80% of parent respondents agreed that, after having a Parent Partner, they were capable of coping with emotional stress regarding their child's treatment procedures. Although not asked directly in the 2015 survey, the smaller survey in 2013 found high levels of satisfaction with services received in the program and with their child's progress over the first six months in the program.

DISCUSSION AND CONCLUSIONS

The Parent Partner Program was implemented in eight practices in Montana and Wyoming with the goal of establishing comprehensive service delivery to families of CSHCN within the pediatric practice setting. The Parent Partner Program is similar in some ways to other programs such as U Special Kids in Minnesota, which centralizes the medical home for CSHCN families in the state [12]. This specific focus on the CSHCN population is common among these and other programs. In contrast to this centralized system established in U Special Kids, the Parent Partner Program integrates Parent Partners into the local, community-based pediatric primary care office, allowing flexibility at the provider-level for fully integrating Parent Partners into their practice. For example, some providers chose to modify their scheduling system to get most CSHCN family appointments on the same day the Parent Partner was in the practice. In addition, the emphasis on establishing an ongoing emotionally supportive relationship with families served is a major difference between the Parent Partner Program and other programs.

The initial evaluation of the Parent Partner Program revealed success in engaging parents in the clinical practice and providing families with needed connections to social supports and services. Parent Partners and parents themselves indicated medium to high levels of parent satisfaction and identification of community resources. The Parent Partner model may also lead to improvements in both clinical needs for families and parent coping, which has been shown to improve when care is provided within a health care or medical home [13]. Other studies have found positive associations between care coordination and

Table 1: Constructs Measured in and Example Questions from the Parent Partner, Parent, and Provider Surveys.

| Construct | Stakeholder Group | Example Questions From Surveys |
|---|-----------------------------|---|
| Parental Awareness | Parent Partners | Parents of patients with special health needs seen in your physician practice setting are aware of the Parent Partner Program. (Scale: 1, strongly disagree – 2, strongly agree) |
| Compliance | Parent Partners | The program is in compliance with applicable professional and legal standards. (Scale: 1, strongly disagree – 2, strongly agree) |
| Adequacy of Resources (financial and non—financial) | Parent Partners | There are adequate resources, facilities, and funding to support important programs for the Parent Partners in your practice setting. (Scale: 1, strongly disagree – 6, strongly agree) |
| Family Satisfaction | Parent Partners and Parents | [Parent Partner Survey] Families served by Parent Partners are satisfied with their Parent Partner (Scale: 1, strongly disagree – 6, strongly agree) [Parent Survey] Overall, how satisfied are you with the services that you receive from your Parent Partner? (Scale: 1, very dissatisfied – 6, very satisfied) |
| Responsiveness to Clients | Parent Partners | How often do you respond to your client in a timely manner? (Scale: 1, never – 6, always) How often do you find it difficult to follow-up with the families you are partnering? (Scale: 1, never – 6, always) |
| Training Implementation | Parent Partners | The objectives of the Parent Partner training were clearly defined at the onset of each training session. (Scale: 1, strongly disagree – 6, strongly agree) The topics covered in the training were relevant to my duties as a Parent Partner. (Scale: 1, strongly disagree – 6, strongly agree) |
| Provider Satisfaction | Provider | I have a positive attitude towards the Parent Partner Program. (Scale: 1, strongly disagree – 6, strongly agree) |
| Practice Implementation | Provider | Families with children with special health care needs are promptly introduced to the Parent Partners after their first clinic visit. (Scale: 1, strongly disagree – 6, strongly agree) |
| Impact on Clinical Practice | Provider | The Parent Partners have improved my efficiency in providing care for children with special health care needs. (Scale: 1, strongly disagree – 6, strongly agree) The presence of a Parent Partner in the room facilitates my discussion with the parents or caregivers. (Scale: 1, strongly disagree – 6, strongly agree) |
| Parental Enthusiasm | Parents | What was your initial level of enthusiasm for participating in the Parent Partner Program? (Response options: very high, high, medium, low, very low) |
| Parent Capacity | Parents | After having a Parent Partner, I become more confident in making decisions and necessary lifestyle changes to achieve optimal health for my child. (Scale: 1, strongly disagree – 6, strongly agree) After having a Parent Partner, I become more capable of coping with emotional stress regarding my child’s treatment procedures. (Scale: 1, strongly disagree – 6, strongly agree) |

Table 2: Respondent Demographics, Parent Survey (n=99).

| Demographic Characteristic | Percent of Respondents |
|--|------------------------|
| Gender (parent or guardian) | |
| Male | 12% |
| Female | 88% |
| Race (parent or guardian) | |
| White | 90.5% |
| African American | 0% |
| Native American | 9.5% |
| Ethnicity (parent or guardian) | |
| Latino/Hispanic | 7.5% |
| Non Latino/Hispanic | 92.5% |
| Primary Language Spoken at Home | |
| English | 99% |
| Spanish | 1% |
| Highest Level of Education (parent or guardian) | |
| Never Attended School | 0% |
| Grades 1-8 | 0% |
| Grades 9-11 | 8.1% |
| Grade 12 or GED | 40.4% |
| College for 1-3 years | 41.4% |
| Bachelor’s Degree | 8.1% |
| Master’s Degree | 2% |
| Doctorate Degree | 0% |

| | |
|---|-------|
| Current Employment Status (parent or guardian) | |
| Unable to Work | 11.5% |
| Employment for Wages | 55.2% |
| Self Employed | 5.8% |
| Out of work, >1 year | 2.3% |
| Out of work, < 1 year | 2.3% |
| Homemaker | 17.2% |
| Student | 3.5% |
| Retired | 2.3% |
| Health Insurance Coverage (child) | |
| None | 3.1% |
| Self-employment Insurance | 0% |
| Employer | 28.6% |
| Privately Purchased Insurance | 1% |
| Coverage Purchased on Health Insurance Exchange | 3.1% |
| COBRA | 0% |
| Medicaid | 64.3% |
| CHIP | 5.1% |
| Other Government | 2% |

parent reported outcomes related to unmet needs and child health [14,15]. These effects may be more profound when care coordination is offered within a medical home [16].

Providers noted that the Parent Partners were key to linking families with these resources that, otherwise, the provider may not know were needed. Additionally, the Parent Partner program appeared to reduce the average amount of time providers spent during a visit with a family of CSHCN. Programs such as the Parent Partner Program may help alleviate known challenges facing physicians. Small practices, such as those known to serve rural communities, report fewer full-time staff dedicated to clinical care and community services coordination [17]. In smaller community-based pediatric practices serving some CSHCN, a full-time care coordinator may not be feasible. However, a part-time Parent Partner with their own experience navigating the local health care delivery system may be a reasonable addition to the practice. Indeed, the Parent Partner may offer a level of service a general care coordinator is unable to provide, given the unique needs of CSHCN families. Further, the addition of a Parent Partner to help families of children with complex needs may help address issues related to physician overload and burnout, especially that which is driven by overall workload.

When MSGRC funding ended, state programs in both Montana and Wyoming committed to continuing support for the program through either state Medicaid support or other public funds. This indicates that the Parent Partner Program is viewed as valuable by multiple stakeholder groups, including policy decision makers in state government.

The program does have opportunities for improvement. The Parent Partner training program could be intensified by providing more frequent training sessions focusing on more specific aspects of the Parent Partner practice. For example, the training could include detail about how patient privacy rules impact day-to-day practice and how Parent Partners can better serve families in certain situations such as those impacted by addiction or at risk of having children placed outside of their parent's home. Such expansions of the training program may enhance the Parent Partners' daily work.

Parent Partner survey respondents also indicated the desire for more routine communication with the provider team, e.g. the Parent Partner, nurse coordinator or case manager, and the physician. Given that providers noted parents sharing challenges with the Parent Partner that they would not share with the physician, ongoing communication between provider team members may improve overall care delivery for CSHCN within the community-based pediatric practice. Early evidence suggests that the addition of Parent Partners is beneficial for families, and may contribute to improving compliance and overcoming barriers unknown to the physician without interactions between the Parent Partner and the family.

This study does have several limitations. First, the cross-sectional surveys and analysis do not allow for assessing trends in stakeholder perceptions or clinical outcomes over time. This should be a focus of future evaluations of this program. Secondly, the program was implemented in pediatric clinical practices in rural communities with potentially fewer resources available for families. The results presented may not be generalizable to other communities or clinical settings. Finally, the response rate to the provider survey was low and the results from that survey, therefore, may not be representative of all participating providers.

Despite these limitations, the study offers early evidence of a promising program targeting a population in need of multiple and diverse health and social services. Parent Partners offer the potential to improve services for families of CSHCN who have both medical and non-medical needs. The Parent Partner Program model, which delegates clinical responsibility to the physician and social service responsibility to the Parent Partner, may strengthen the medical home for these families while maximizing the training and experience of those serving them. Other community-based pediatric practices serving families of CSHCN could consider the Parent Partner Program or similar models to improve overall care for these families.

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