Adoption Advocate

National Council For Adoption

NICOLE FICERE CALLAHAN, EDITOR
CHUCK JOHNSON, EDITOR
ELISA ROSMAN, PH.D., EDITOR

NO. 32 • FEBRUARY 2011

A PUBLICATION OF THE NATIONAL COUNCIL FOR ADOPTION

Adopted Children with Special Health Care Needs: National Survey Findings

by Amy McKlindon, Kate Welti, Sharon Vandivere, and Karin Malm†

Introduction

The 2008 National Survey of Adoptive Parents of Children with Special Health Care Needs (NSAP-SN) provides nationally representative information about the health and wellbeing of adopted children with special health care needs (CSHCN) and their families. Children are identified as having a special health care need if they experienced one or more of five health care consequences as the result of a chronic health condition lasting (or expected to last) at least 12 months: ongoing use of prescription medications; higher than normal health care service utilization; activity limitations; specialized therapies; and treatment or counseling for a behavioral or emotional problem (Bramlett et al., 2010).

Building on previous work that compared CSHCN in the general population and all adopted CSHCN,[2] the present article makes comparisons among CSHCN adopted in three different ways: through foster care adoption, private domestic adoption, and international adoption. Children adopted from foster care are those who, prior to their adoption, were involved with the child protective services system and removed from their families due to their parents' inability or unwillingness to provide appropriate care.

ABOUT THE DATA

The NSAP-SN is the result of a collaboration of the Office of the Assistant Secretary for Planning and Evaluation (ASPE), the Administration for Children and Families (ACF), and the National Center for Health Statistics (NCHS), and was conducted as a follow-back to the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). Families were initially identified for the NS-CSHCN if any child in the household had a special health care need. Parents were then eligible to participate in the NSAP-SN if the focal child from the NS-CSHCN interview was adopted and lived in an English-speaking household. Additionally, because it was conducted two to three years after the NS-CSHCN, which interviewed parents of children under age 18, the NSAP-SN is nationally representative of adopted CSHCN ages zero to fifteen in 2005-06.[1]

A total of 1,007 phone interviews were conducted for the NSAP-SN from February to July 2008, for a completion rate of 67.3 percent; the overall response rate, taking into consideration non-response to NS-CSHCN, was 37.7 percent. In addition to being limited by non-response bias, findings are limited by coverage bias and the fact that parent's reports of their child's health care needs were not confirmed with health care professionals.

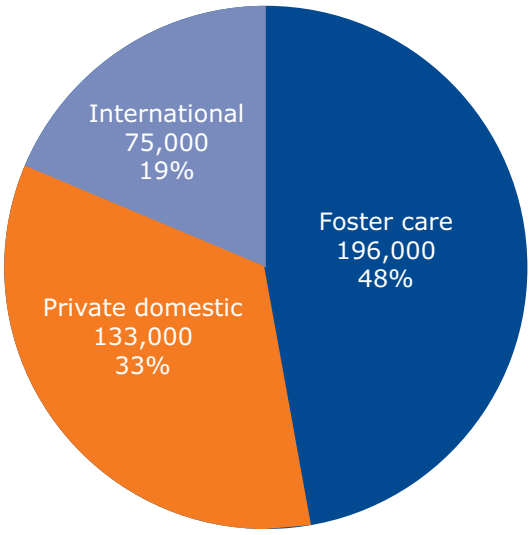
Survey data yielded information on the characteristics and wellbeing of the adopted child and family, adoption agreements, and post-adoption services and supports.

[1] Bramlett et al. (2010) provide further information on the methodology of the NSAP-SN.
[2] See Bramlett & Radel (2008).

Public child welfare agencies oversee such adoptions, although they may contract with private adoption agencies to perform some adoption functions. Other children adopted from within the United States who were not in the foster care system at any time prior to their adoption joined their family through private domestic adoptions. These adoptions may be arranged independently or through private adoption agencies. Children adopted internationally originated from countries other than the United States; typically, their adoptive parents work with private U.S. adoption agencies, which coordinate with adoption agencies and other entities in the children's countries of origin.

In 2008, there were over 400,000 adopted CSHCN, representing 39 percent of all adopted children. Previous analyses based on the National Survey of Children with Special Health Care Needs (NS-CSHCN), have shown that adopted CSHCN are more likely than the broader population of all CSHCN to be identified as CSHCN on the basis of elevated need for services; physical, occupational, and/or speech therapy; behavioral, developmental, and/or emotional problems requiring treatment or counseling; or limitation in activity (but not on the basis of elevated prescription medication use). Additionally, they are more likely than the general population of CSHCN to meet multiple screening criteria (Bramlett & Radel, 2008). Almost half of adopted CSHCN were adopted from foster care, one in three was adopted from private domestic sources, and the remaining CSHCN were adopted internationally; see Figure 1. Survey findings indicate that the majority of adopted CSHCN have parents who are satisfied with their adoption experience and their relationship with their child, and also perceive their child as having a positive view of adoption. Differences do emerge across adoption types, including variation in the types of services received after adoption and need for additional services.

Figure 1: Number and percentage distribution of adopted CSHCN by adoption type



Children's History, Prior Relationship with Parents

Adopted CSHCN live in a variety of settings prior to their adoptive placements, and those settings vary by adoption type. Almost half of adopted CSHCN lived with birth family members at some point prior to adoption, and this experience also varies by adoption type.

Children[3] adopted from foster care are nearly twice as likely as those adopted internationally to have lived in a foster home (39 compared with 21 percent), and they are also more likely to have lived with birth family members or relatives immediately prior to adoptive placement (26 compared with three percent).[4] Approximately three out of four (74 percent) CSHCN adopted privately within the United States were adopted at birth or within one month of birth, while the majority of CSHCN adopted internationally lived in a congregate care setting (74 percent) prior to adoption.

Just under half (46 percent) of adopted CSHCN lived with birth family members at some point prior to adoption. CSHCN adopted from foster care are the most likely to have lived with birth family members (64 percent), compared with children adopted from private domestic sources (32 percent) and internationally (24 percent).

Overall, 19 percent of adopted CSHCN were adopted by relatives, and 18 percent were adopted by nonrelatives who previously knew the child. CSHCN adopted privately in the United States are the most likely already to have been related to their parent prior to adoption, whereas those adopted from foster care are the most likely to have a parent who was not previously related to the child, but who knew the child. Among CSHCN who were adopted by their foster parents, 43 percent have parents who had become foster parents in the hopes of adopting.

Transracial, Transethnic, and Transcultural Adoptions

The survey asked parents whether their child was of a different race or ethnicity or from a different culture than they themselves, and whether the child was of a different race or ethnicity or from a different culture than the respondent's spouse/partner (if applicable). Over one-third (36 percent) of adopted CSHCN differ racially, culturally, or ethnically from their parent (and their parent's spouse/partner, if applicable); these are children who were adopted transracially, transculturally, or transethnically. Among the three groups, children adopted internationally are the most likely to be in transracial adoptions (78 percent), compared with children adopted from foster care (28 percent) and children adopted privately within the United States (26 percent).

Among CSHCN adopted internationally, Asia and Europe are the two most common regions of origin, with 58 percent and 37 percent of children originating from these areas, respectively. One in four (25 percent) internationally adopted CSHCN was adopted from China, and 21 percent were adopted from Russia.

Family Structure

Over half of adopted CSHCN live with two married parents. The majority of adopted CSHCN have known birth siblings, and one in four has at least one birth sibling also adopted by their parent. The presence of birth siblings and other children in the household varies by adoption type.

Fifty-two percent of adopted CSHCN live with two married parents. Internationally adopted CSHCN are the most likely to live with two married parents (61 percent), compared with those adopted from foster care (52 percent) and from private domestic sources (46 percent).

While 25 percent of adopted CSHCN have at least one birth sibling who was also adopted by their parent, this varies by adoption type and is

[3] All findings pertain to adopted children with special health care needs; we use the term children for brevity.
[4] All differences described in the text are statistically significant at $p<.05$, unless otherwise noted.

most common for CSHCN adopted from foster care; see Figure 2. Among the three groups, CSHCN adopted internationally are the most likely to have parents who did not know whether the child's birth siblings were ever available for adoption (35 percent). Almost half (46 percent) of children adopted privately within the United States have birth siblings who were never available for adoption.

The majority of adopted CSHCN (85 percent) live with other children in the household. Those adopted from foster care are the least likely to be the only child in the family (10 percent, compared to 19 percent and 20 percent of children adopted privately in the United States or internationally, respectively) and the most likely to live with both adopted siblings and siblings born to the parent (40 percent, compared to 22 percent and 20 percent of children adopted privately in the United States and internationally, respectively). CSHCN adopted privately within the United States are the most likely to live with siblings born to their parent but with no adopted siblings (34 percent, compared to 20 percent and 21 percent of children adopted from foster care and internationally, respectively).

Parenting and Parental Wellbeing

The majority of adopted CSHCN have a parent who feels that his/her relationship with the child is very warm and close.

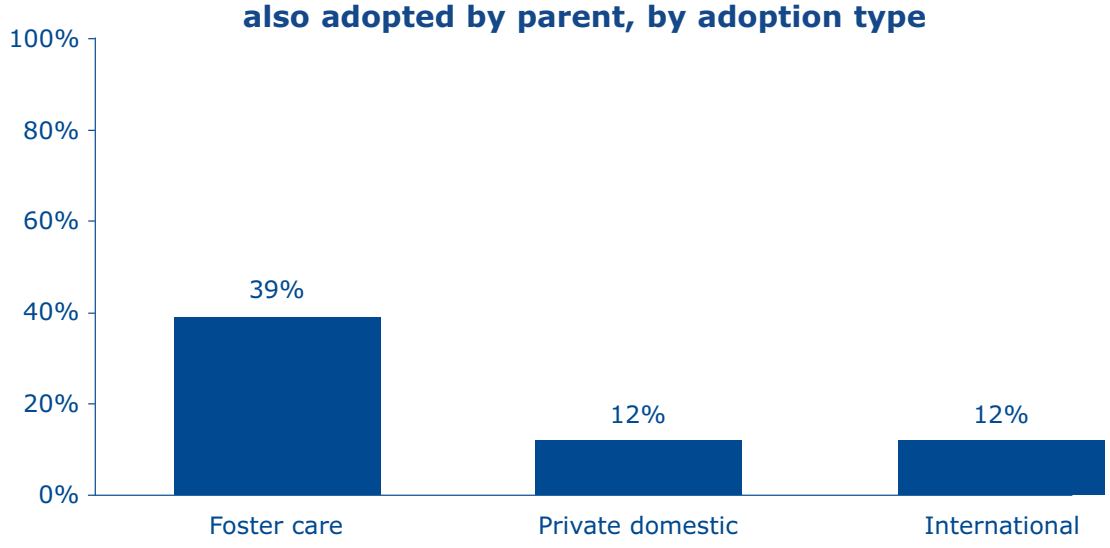
Seventy-one percent of adopted CSHCN have a parent who feels that the parent-child relationship is very warm and close, and 26 percent have a parent who feels that the relationship is better than ever expected. Approximately four in ten children (42 percent) have parents who feel that having the child in their life is better than they ever expected.

Parents do experience some challenges, however; approximately one in three children (32 percent) have a parent who describes the parent-child relationship as more difficult than they ever expected, and 28 percent have a parent who feels that having the child in their lives is more difficult than they ever expected.

Adoption Satisfaction

The vast majority of parents adopting CSHCN would probably or definitely make the same decision to adopt their child, with slight variation by adoption type. Parents also feel that

Figure 2: Percentage of adopted CSHCN with birth siblings also adopted by parent, by adoption type



their adopted children have positive feelings about adoption.

Among adopted CSHCN, 78 percent of children have a parent who would "definitely" make the same decision to adopt, and an additional 17 percent would "probably" make the same decision. CSHCN adopted privately within the United States were the most likely to have a parent who would "definitely" make the same decision to adopt (89 percent), compared with CSHCN adopted from foster care (74 percent) and internationally (72 percent); see Figure 3.

Parents of children ages five and older were also asked about their perceptions of the child's feelings about adoption, and over nine out of ten children have a parent who feels that their child has positive or mostly positive feelings. Children's feelings about adoption, as reported by parents, do not differ by adoption type.

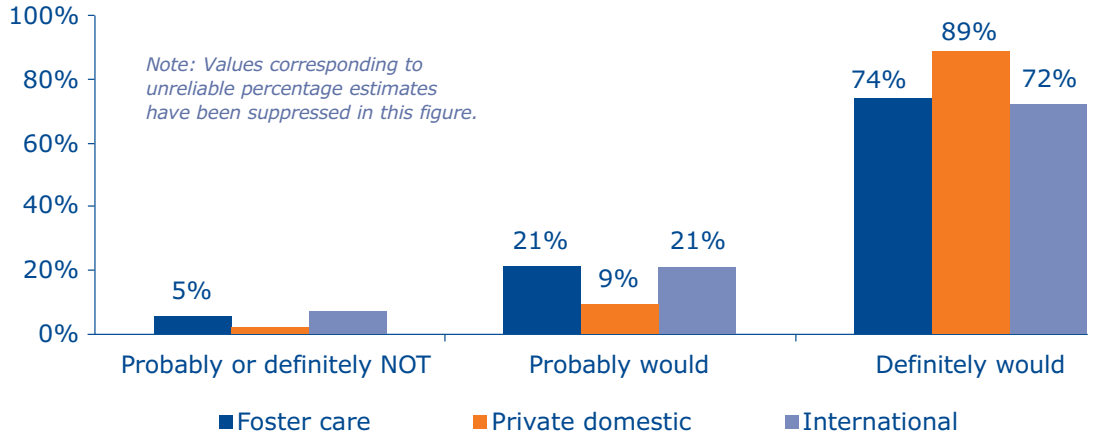
Parental Involvement/Advocacy in Adoption Community

While most families of adopted CSHCN were not asked to help or recruit other adoptive families, some families were involved in these activities. Involvement varied by adoption type. It is most common for parents to be involved in helping other adoptive families (46 percent), as compared to recruiting other adoptive families (10 percent). CSHCN adopted internationally are the most likely to have a parent who helped other families (65 percent, compared with 41 percent each of CSHCN adopted from foster care or internationally). While the majority of adopted CSHCN have parents who were not asked to recruit other adoptive families, CSHCN adopted from foster care were the most likely to have a parent involved in recruitment efforts (16 percent).

Parents' Prior Connections to Adoption

Three out of four adopted CSHCN have parents with a prior connection to adoption (see Figure 4), and there were no significant differences by adoption type. While parents could describe multiple prior connections to adoption, the closest connection is reported in Figure 4. It is most common for children to have a parent with a relative outside of his/her immediate family who was adopted.

Figure 3: Percentage of adopted CSHCN according to whether their parents would make the same decision to adopt again, by adoption type



Parents' Motivation to Adopt

Parents of adopted CSHCN are motivated to adopt by a variety of different factors, and the most common motivations included wanting to provide a permanent home for a child, wanting to expand their family, and/or infertility. Motivations to adopt differ by adoption type; see Figure 5.

Children adopted from foster care are less likely than children adopted privately within the United States or children adopted internationally to have parents who were motivated to adopt by infertility (35 percent, compared to 55 percent and 57 percent, respectively).

Children adopted internationally are more likely than children adopted from foster care or privately within the United States to have parents who wanted a sibling for their child (40 percent, compared to 20 percent and 22 percent, respectively) or wanted to expand their family (90 per-

Figure 4: Percentage distribution of adopted CSHCN by parents' prior connection to adoption

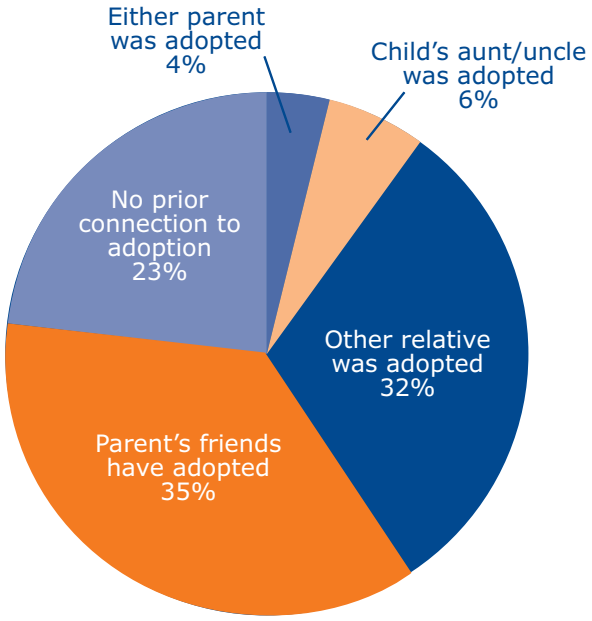
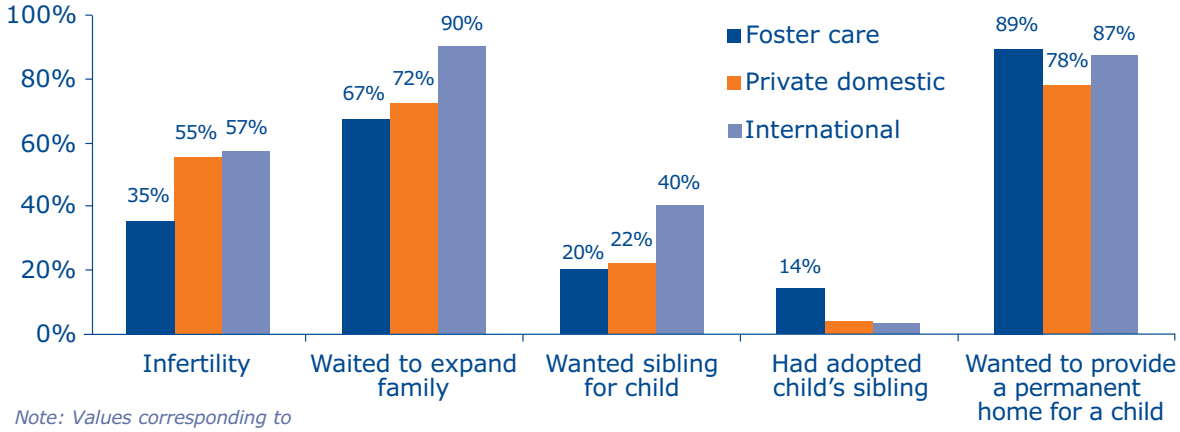


Figure 5: Percentage of adopted CSHCN by parents' reasons for choosing to adopt, by adoption type



Note: Values corresponding to unreliable percentage estimates have been suppressed in this figure.

cent, compared to 67 percent and 72 percent).

Parents' Satisfaction with Attorney or Agency

The majority of adopted CSHCN (87 percent) have parents who had positive or very positive experiences with their attorney or agency, with no differences according to adoption type. Among all adopted CSHCN, 11 percent have parents who felt that important information was not disclosed to them prior to the adoption, and this was slightly more common among CSHCN adopted from foster care.[5]

Adoption Expenses

Adoption-related expenses vary greatly depending on adoption type, and they tend to be lowest for CSHCN adopted from foster care. Many adopted CSHCN have parents who received some type of assistance with adoption expenses.

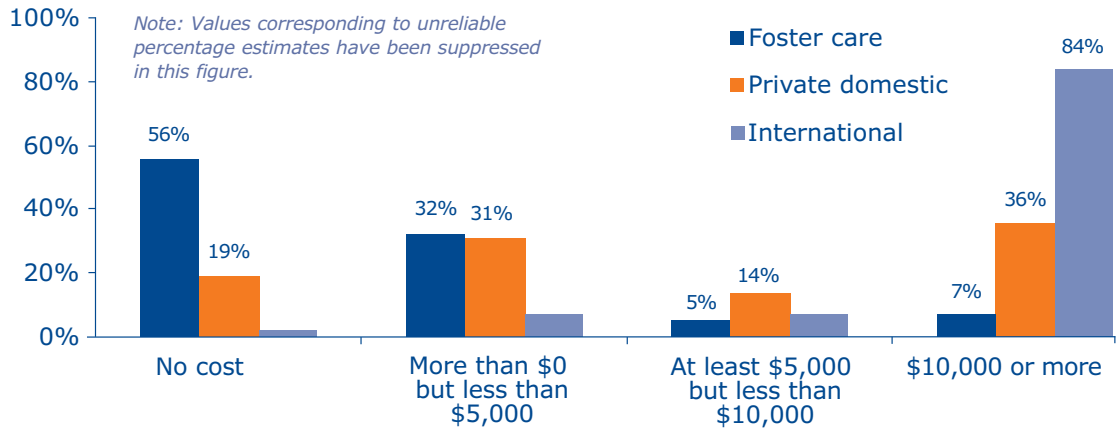
One-third of adopted CSHCN have parents who incurred no adoption-related expenses, while three out of ten have parents who incurred expenses of $10,000 or more. CSHCN adopted from foster care are the most likely to have parents who paid no adoption expenses (56 percent), while CSHCN adopted internationally are the most likely to have parents who paid $10,000 or more in adoption-related expenses (84 percent); see Figure 6.

Parents may have received assistance with adoption-related expenses from the federal adoption tax credit, agency reimbursement (for foster care adoptions), and/or employer assistance. Three out of four adopted CSHCN have parents who filed for the federal adoption tax credit.[6] Although 37 percent of CSHCN adopted from foster care have parents who were reimbursed for some or all of the cost of adoption from their agency, they are the least likely to have parents who received financial assistance from their employers (six percent, compared with 12 percent and 18 percent for children adopted privately in the United States and internationally, respectively).[7]

Adoption Openness

The majority of adopted CSHCN know that they are adopted. Among CSHCN adopted by

Figure 6: Percentage distribution of adopted CSHCN according to the cost of the adoption, by adoption type



[5] The difference in the percentages of CSHCN adopted from foster care and those adopted from private domestic sources or internationally is marginally significant (p<.10).
[6] Children whose adoptions occurred before this tax credit was available (prior to 1997) are excluded from this analysis.
[7] The difference in the percentage of CSHCN adopted from foster care and CSHCN adopted from private domestic sources is marginally significant (p<.10).

nonrelatives, fewer than half have a pre-adoption agreement regarding openness or have had post-adoption contact with birth families.

Ninety-seven percent of adopted CSHCN ages five and older know that they are adopted. This differs slightly across adoption types, with privately adopted U.S. CSHCN less likely to know that they are adopted (94 percent).[8]

Among CSHCN adopted by nonrelatives, 36 percent have a pre-adoption agreement regarding openness and 44 percent have had post-adoption contact with birth relatives. CSHCN adopted privately within the United States are the most likely to have a pre-adoption agreement and post-adoption contact; see Figure 7.

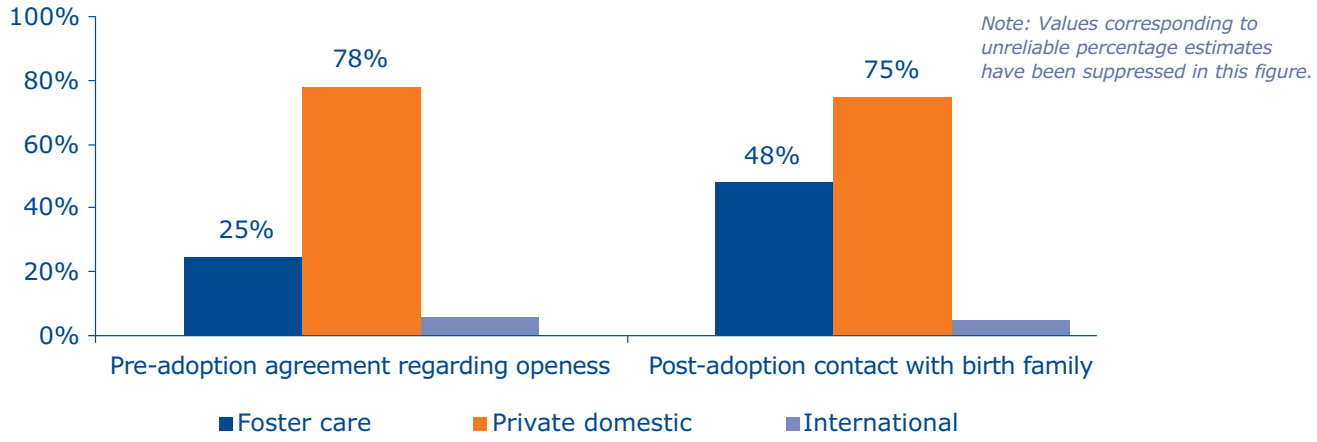
Post-Adoption Supports

Adoption-Specific Supports

Survey findings indicate that among adoption-specific supports (i.e., meeting with someone at the agency to discuss post-adoption services, child support groups for ages five and older, parent support groups, and training for parent), the most commonly received service was meeting with someone at the agency to discuss post-adoption services. Receipt of services varies by adoption type, and over one in three adopted CSHCN have parents who needed at least one adoption-specific support that was not received post-adoption. Most CSHCN adopted from foster care received additional supports in the form of medical insurance and subsidies.

CSHCN adopted privately within the United States are less likely than the other two groups to have received certain adoption-specific supports, including training for the parent (22 percent, compared to 42 percent and 39 percent for children adopted from foster care and internationally, respectively); see Figure 8. Compared with internationally adopted CSHCN, these children are also less likely to have participated in child support groups or to have a parent who participated in a parent support group.[9] Internationally adopted CSHCN are the most likely to have parents who used web-based resources (57 percent, compared to 34 percent and 29 percent for children

Figure 7: Percentage of CSHCN adopted by non-relatives who have pre-adoption agreements regarding openess and who have had post-adoption contact with birth family members, by adoption type



[8] The difference in percentages of CSHCN adopted from private domestic sources and CSHCN adopted from foster care is marginally significant (p<.10)

[9] The difference in percentages of CSHCN adopted from private domestic sources and CSHCN adopted internationally participating in child support groups is marginally significant (p<.10).

adopted from foster care and privately in the United States, respectively).

Thirty-five percent of adopted CSHCN have parents who needed at least one adoption-specific post-adoption service that was not received. Support groups for children were the most common service that parents wanted to receive but did not; see Figure 9. CSHCN adopted from foster care were the most likely to have parents who did not receive a needed adoption-specific support (44 percent, compared to 25 percent and 32 percent of children adopted privately in the United States and internationally, respectively).

The majority of CSHCN adopted from foster care receive health insurance and an adoption subsidy through an adoption agreement. Eighty-one percent of CSHCN adopted from foster care have an adoption agreement guaranteeing health insurance coverage and a subsidy, and 82 percent currently receive a subsidy.

Figure 8: Percentage of adopted CSHCN whose parents received various post-adoption services (adoption specific) by adoption type

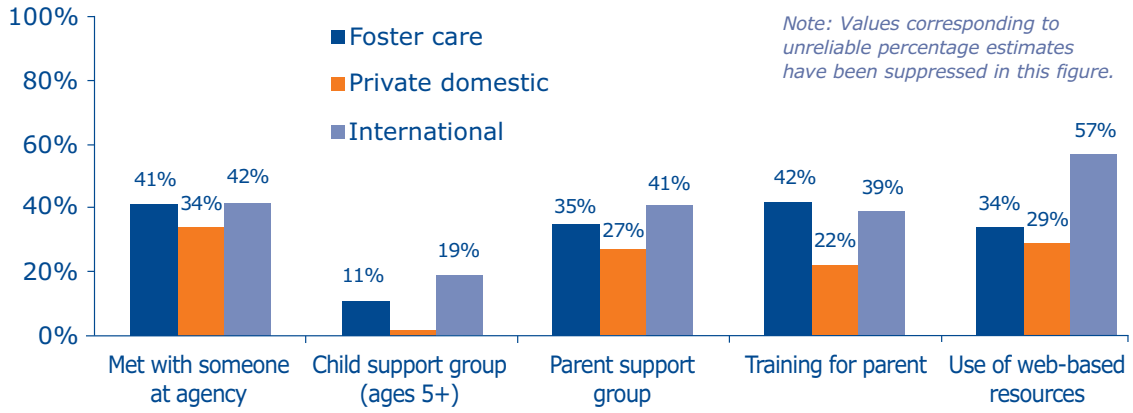
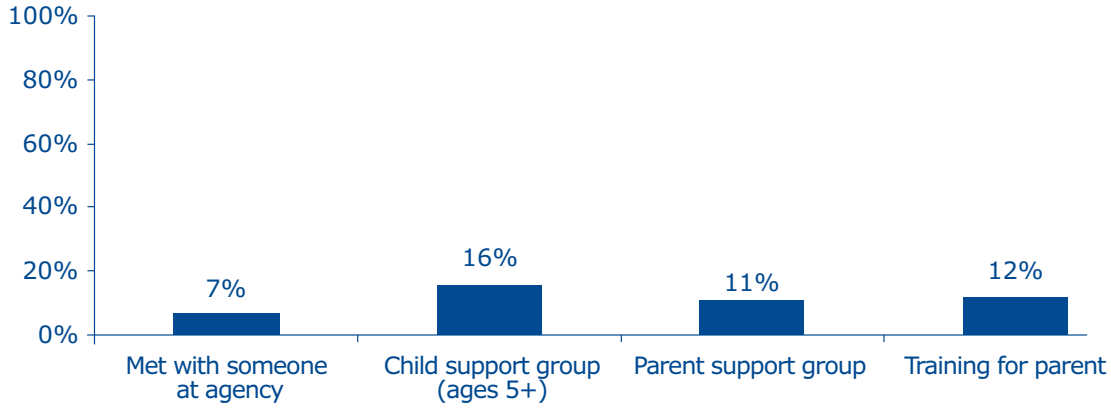


Figure 9: Percentage of adopted CSHCN whose parents wanted to receive various post-adoption services (adoption specific) but did not



Rehabilitative Services and Other Services Not Specific to Adoption

The NSAP-SN also asked whether families received rehabilitative services not specific to adoption (i.e., family counseling, crisis counseling, mental health care for children ages five and older, psychiatric residential treatment/ hospitalization for children ages eight and older, drug/ alcohol services for children ages 13 and older, and mentors or tutors for children ages five and older). Two out of three adopted CSHCN and their families received at least one rehabilitative or general service, most commonly mental health care for the child (67 percent). Children ages 12 to 17 are more likely to have received these services than children ages five to 11.

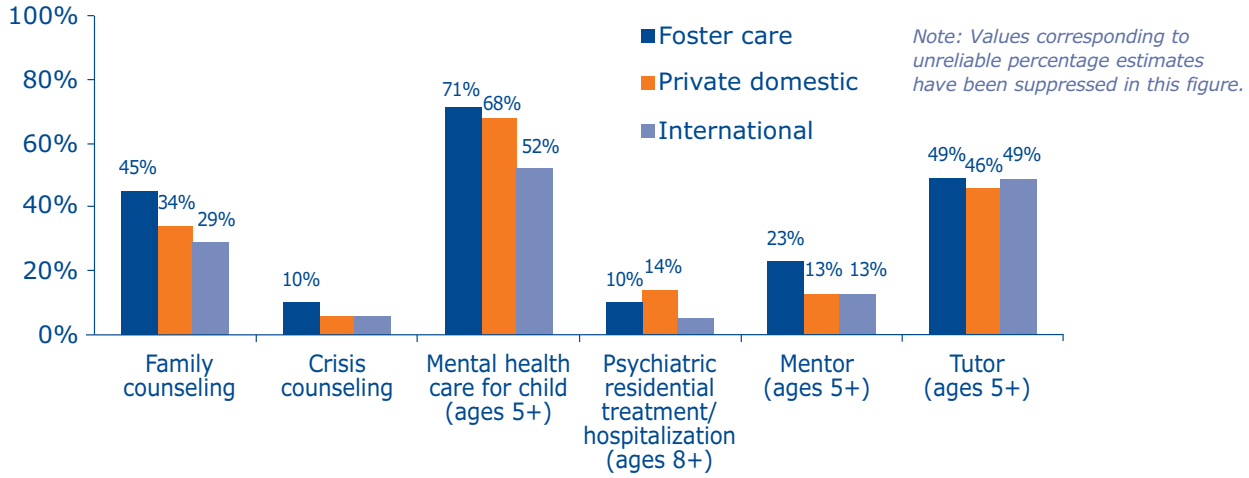
Receipt of services varies by type of adoption; see Figure 10. CSHCN adopted internationally were the least likely to receive at least one rehabilitative service (54 percent, compared to 72 and 69 percent of children adopted from foster care and internationally, respectively). CSHCN adopted from foster care are more likely to have received family counseling, mental health services, and to have a mentor than CSHCN adopted internationally or privately within the United States.[10]

Twenty-six percent of adopted CSHCN have parents who needed but did not receive at least one support (not specific to adoption) post-adoption. CSHCN adopted from foster care are more likely to have a parent report an unfilled need (31 percent) than are those adopted internationally (17 percent). Among all adopted CSHCN, tutoring and mentoring services were the most commonly desired general services that were not received.

Conclusion

CSHCN represent an important segment of the population of adopted children in the United States, as almost four in ten adopted children (39 percent) have special health care needs (Vandivere et al., 2009). The survey findings presented here provide nationally representative information about their characteristics and their families' adoption experiences. However, it is important to note that these findings are represen-

Figure 10: Percentage of adopted CSHCN whose parents received various post-adoption services (general) by adoption type



[10] The percentage difference between CSHCN adopted from foster care and CSHCN adopted from private domestic sources was marginally significant for receipt of family counseling and mental health care services (p<.10).

tative of adopted CSHCN, not all adopted children.[11] The majority of adopted CSHCN have parents who feel that their parent-child relationship is very warm and close and that their adopted children view adoption positively as well. While many parents received adoption-related and non-adoption-related services after finalization, there are still gaps in services.

The NSAP-SN also allows for comparisons across adoption types, which points to some variation in experiences before, during, and after adoption depending on the type of adoption. For instance, CSHCN's living arrangements prior to the adoption and prior relationships with birth family members and adoptive parents vary depending on the type of adoption, as do parents' motivations to adopt. At the time of adoption, differences can be seen in the cost of the adoption, forms of financial assistance utilized by parents, and whether or not the family has an agreement regarding openness with the birth family. Post-adoption, there is variation in the types of services received by the child and family and their desire for additional services.

References

Bramlett, M.D., Brooks, K.S., Foster, E.B., et al. (2010). Design and operation of the National Survey of Adoptive Parents of Children with Special Health Care Needs, 2008. *Vital Health Statistics*, *1*(51). Retrieved from http://www.cdc.gov/nchs/data/series/sr_01/sr01_051.pdf

Bramlett, M.D., and Radel, L.F. (2008). *ASPE Research Brief: Adopted children with special health care needs: Characteristics, health, and health care by adoption type*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, Office of Human Services Policy – U.S. Department of Health and Human Services. Retrieved from http://aspe.hhs.gov/hsp/08/CSHCN/rb.shtml

Vandivere, S., Malm, K., and Radel, L. (2009). Adoption USA: *A Chartbook Based on the 2007 National Survey of Adoptive Parents*. Washington, D.C.: The U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

[11] *Adoption USA*: *A Chartbook Based on the 2007 National Survey of Adoptive Parents* (Vandivere et al., 2009) provides further information on the wellbeing and adoption experiences of all adopted children.

Visit us at www.adoptioncouncil.org/events for more information.

Every year at NCFA's annual conference, leaders in the field of adoption learn what is happening at the forefront of adoption policy and practice and how they can play an active role in improving and safe-guarding adoption. This year, we are adding educational tracks that provide prospective adoptive parents with the unique opportunity to learn about the latest research on various topics surrounding adoption, as well as resources available to them pre- and post-adoption.

NCFA is committed to producing professional, educational conferences of the highest caliber. We invite adoption professionals and prospective adoptive parents to join us for a 3-day learning experience that promotes best practices and sound policies in adoption and educates attendees on pertinent adoption-related research in the areas of domestic, intercountry, and adoption out of foster care.

HELP US FUND THE *ADOPTION ADVOCATE*

National Council For Adoption is a non-profit organization supported by charitable donations. To maintain our outstanding programs, we accept contributions of every size. To make a contribution, please go to www.adoptioncouncil.org and click on "Contribute" or mail your check to NCFA, 225 N. Washington Street, Alexandria, VA 22314. Thank you!

†The authors are all with Child Trends in Washington, DC.