



Mercy Notes

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Young Caregivers

Over 65 million people in the U.S. spend an average of 20 hours each week caring for chronically ill, disabled or elderly family members. Over one million of those family caregivers are under the age of 18.

This may be a conservative estimate due to the sensitivity of the subject. We hear little to nothing about the kids who care for parents or siblings. These families protect their privacy, often for fear of being split up by child protective services.

The majority of research on caregivers focuses on those who are 18-years-old and over. The findings are clear on the need for support and respite from the emotional and physical toll of caregiving. Many caregivers suffer poor health, and the National Family Caregivers Association reports well over half suffer symptoms of depression. Imagine that burden on the shoulders of a young child or teen.

This issue of *Mercy Notes* looks at two groups of young caregivers: those who care for ill or disabled family members, and those forced by parental abuse and neglect to care for themselves and their siblings.

The Consequences

The first large-scale national survey of child caregivers was released in September 2005 by the National Alliance for Caregiving. *Young Caregivers in the U.S.* explored both positive and negative effects on the children involved. The goal was to learn



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photo by Hector Landeta

about the unique vulnerabilities of caregiving kids and the families they love, and then to share that insight with social service and health care providers.

Among the findings, young caregivers range from age 8 to 18 and tend to live in lower income, one parent households. Caregiver gender is almost evenly divided between boys and girls, and most care for parents or grandparents. The family members they care for have Alzheimer's disease, cancer, heart disease and other illnesses. Some help care for ill or disabled siblings. Caregivers help with bathing, dressing, toileting, feeding, giving medications and household tasks. Some are also liaisons for adults with health care and other service providers. Most young caregivers say someone else in the home helps provide care, though minority caregivers are more likely to have no help.

The majority of kids surveyed felt appreciated for their efforts. The few media stories on them note caregiving kids feel more mature and better able to handle life's challenges than their peers. On the downside, they are more likely than noncaregivers to be anxious, depressed and feel unloved, and they are sometimes fatigued to the point of illness. They are also more likely to struggle with school work or behavior problems, though they may simply look like kids with bad attitudes or neglectful parents.

Young caregivers struggle to keep up in school and are at high risk of dropping out. A 2006 Civic Enterprises study found 22 percent of students who left high school had to care for family members. Attending college or launching a career takes a back seat to family duties, and caregivers are likely to earn less income throughout their adult years than their peers.

Their Stories

Almost 15 million Americans care for family members with Alzheimer's or other dementia, with 80 percent of that care provided at home. In 2003, at least 250,000 Alzheimer's caregivers were under the age of 18. Alzheimer's caregivers suffer high levels of stress and exhibit symptoms of depression, requiring almost \$8 billion in extra medical care in 2010. Read about two young caregivers whose parents suffer this disease at www.cnn.com. Read the stories of other kids who care for ailing adults or disabled siblings at www.nytimes.com and www.therecord.com, respectively.

Abused and Neglected Young Caregivers

Lutheran Family and Children's Services of Missouri (LFCS) helps many child caregivers you are even less likely to hear about—kids suffering abuse and neglect by parents. Forced to take on adult responsibilities just to survive, these children cook, clean house, do laundry and raise their siblings. Like the kids providing care to ailing family members, they often keep their situations secret. LFCS shared the stories of two awesome young women who cared for themselves and their younger siblings. Their names are changed to protect their privacy.

Jean

Jean feels her childhood was taken from her. She never told anyone about her mother's drug abuse, hiding the neglect she and her little sister suffered. Fear, shame and her dignity kept her silent. By age 10, Jean served as the mom of the house, preparing meals, cleaning house, doing the laundry, taking care of her little sister, getting her sister and herself to school each day, and "mothering" their mother. She was a top student, but as her mother's drug abuse worsened, Jean's stress was manifested as behavioral problems at school. When she finally opened up to a school counselor and supportive adults in her school and church, she found the love and encouragement she could not find at home.

Jean is now a busy single mom attending college, working and raising a toddler. She continues to work on maintaining healthy relationships and good boundaries with her family, and she gives back to LFCS by volunteering with a teen support group, reaching out to help other youth. How did Jean become a strong, resilient woman? She was determined to take care of her sister and grow up to be a successful, happy adult. She said, "I knew God had a plan for me, . . . and I knew God was going to get me through this. I am a stronger and wiser person, and I never feel sorry for myself. All the obstacles I have faced made me the person I am today. They inspire me to give my all and do my best."

Kim

As a child, Kim struggled with shame and resentment because her mother abused drugs and inflicted tremendous physical and emotional abuse on Kim and four younger siblings. She was 10 years old when she became the "surrogate mother and housekeeper" for herself and her siblings. She worked very hard in school, counting on education as her way out. Kim said confiding in a school counselor "gave me a chance at a normal life, but I had to go against all I had been brainwashed to believe. I felt like the whole world was against me." Kim found the caring adults and support she needed, including a devoted foster mom, who made a big difference in her life.

Like Jean, Kim finished high school and is now in college. Though busy with school and a full-time job, she, too, gives back to LFCS by volunteering with a teen support group. How did Kim become the strong young woman she is today? She answered with these words: “The Lord, my siblings, and the fact that being overwhelmed wasn’t an option. My experience made me an adult way before my time. Nothing that life threw at me compared to what I’ve been through. I’m empowered to hit everything head on.”

How We Can Help

Asked what resources she suggests to help young caregivers, Jean responded, “The best resources are just support and love. They need positive people in their lives to help them understand what is happening and that it’s not their fault . . . and [that there is] a way to still be children.” Kim added, “They need knowledge so they understand their rights and options.”

Rev. Alan Erdman, president and CEO of LFCS, discussed the young caregivers his agency sees:

“These children are robbed of the opportunity of being just children. They experience an inordinate amount of responsibility, which many times brings anxiety and guilt that they cannot solve nor address about adult problems. It is sad to think of children who do not have a safety net of love, guidance and role modeling to help them develop into the people that God intends for them to be. The other aspect of these kids is the socialization opportunities they miss out on, like after school activities and sporting teams, because they must care for someone in the family. This is one of those issues that children are taught not to discuss. It is simply expected of them.”

Both groups of young caregivers struggle with responsibilities they are not equipped to handle—responsibilities that overwhelm adult caregivers. In *Young Caregivers in the U.S.*, the authors suggest providers of social services and health care partner with organizations already serving families, such as schools, recreation centers and religious groups. There is some speculation that the return of wounded and disabled veterans from Iraq and Afghanistan will increase the number of young caregivers. As injured veterans return home, pastors might raise awareness of the need for support and assistance for these families. In our congregations, Lutheran youth groups might explore outreach to young caregivers in their communities.

Eileen Long, a social worker for LFCS who works with Jean, Kim, and other clients like them, says these young people need ongoing emotional support and mentoring from caring adults in the community. Adults who are able can volunteer for Big Brothers/Big Sisters, mentor teens through programs at local high schools or churches or volunteer to tutor those struggling with schoolwork.

Further Reading

Find *Young Caregivers in the U.S.* at www.caregiving.org/data/youngcaregivers.pdf.

The American Association of Caregiving Youth, a nonprofit organization in Palm Beach, Fla., is a support network created to provide nationwide services for young caregivers. The director, a nurse and former child caregiver, discusses the kinds of support child caregivers need at www.npr.org. Learn more about the group here: www.aacy.org.

Sources: Alzheimer’s Association, American Association of Caregiving Youth, American Psychological Association, Arizona Public Media, CNN, Lutheran Family and Children’s Services of Missouri, NPR, National Alliance for Caregiving, National Family Caregivers Association, National Multiple Sclerosis Society, *New York Times*, *The Record*

Obama’s One-Two Punch to Marriage and Family

Shortly after announcing the Department of Justice will no longer defend the Defense of Marriage Act (DOMA), the federal law that protects marriage as the union of one man and one woman, the Obama administration announced its intent to give your right to decide how to parent your children to foreign authorities. On March 10, the Obama administration promised the UN Human Rights Council that it will press for U.S. ratification of the Convention on the Rights of the Child (CRC) www.congress.org. The CRC would invalidate most U.S. laws for children and families, imposing the oversight of 18 international

experts in Geneva on all parental decisions. Read more here <http://parentalrights.org> on how this would alter your family's life. Find out if your senator has signed S. Res. 99 www.govtrack.us, a resolution not to ratify the CRC.

From the Hill

- House Minority Leader Nancy Pelosi (D-Calif.), a member of the House Bipartisan Legal Advisory Group created to defend DOMA, told Speaker John Boehner by letter that Congress should be focusing on jobs, not spending money defending marriage www.sfgate.com. She also signed on as one of 110 Democratic cosponsors of the **Respect for Marriage Act (H.R. 1116)**, introduced by Rep. Jerrold Nadler (D-NY) March 16 to repeal DOMA. The Senate version is **S. 598**, introduced by Sen. Dianne Feinstein. Read Speaker Boehner's response to Pelosi <http://thehill.com>.
- The president of the National Association for Home Care & Hospice warns that new federal regulations on Medicare coverage of home health care will be devastating for seriously ill and homebound older adults and will increase health care costs. <http://thehill.com>.
- The Department of Veterans Affairs began a new National Caregiver Support Line on Feb. 1. Veterans' caregivers can call toll free and speak to licensed clinical social workers, who will answer questions and provide referrals to caregiver coordinators in local VA Medical Centers. Learn more here: www.caregiver.va.gov.
- President Obama is urging increased domestic oil exploration and production to combat rising gas prices, so why did Wyoming's Forest Service Supervisor abruptly cancel federal oil and gas leases in the Bridger-Teton National Forest? Rep. Cynthia Lummis (R-Wyo.), a member of LCMS, brought this troubling federal double-speak to constituents' attention. Read <http://lummis.house.gov>.

State Watch

- As mentioned in the November 2010 issue of *Mercy Notes*, parents in Helena, Mont., were outraged by the school board's plan to begin a graphic sex education program for children beginning in kindergarten. Planned Parenthood was a key participant in the program's design. School board officials plan to proceed, so parents and state legislators are pursuing legislation to strengthen parental rights. Read more at www.onenewsnow.com.
- Efforts to legalize same-sex marriage in Maryland failed, thanks to the efforts of citizens, the Catholic Church and other religious leaders. Read the story at www.aolnews.com. A disconnect in how citizens and elected officials see this issue was revealed by a frustrated lawmaker, "If people were voting based on their conscience and not on their constituents, this would be over with."
- Washington issued a report on its physician-assisted suicide law, in effect since March 2009. The report revealed the scant oversight required by the state. There is no verification for whether those who died consented to their deaths. More alarming, heirs can help relatives sign up for assisted suicide with no oversight to prevent coercion or abuse. Read more at www.lifenews.com.

Learn More

Visit <http://thomas.loc.gov> for the complete text of bills and for further information, including the current status of any bill and the names of sponsoring representatives.

To find out how your representatives voted on recent legislation, visit www.vote-smart.org.

Contact Your Elected Officials

For the name of your U.S. representative or senator, contact your local elections officer or call the **Federal Citizen Information National Contact Center at 800-333-4636**.

For the most recent information about elected national officials, visit to these websites or call the following Capitol switchboard numbers:

Senators

202-224-3121 • www.senate.gov

Representatives

202-225-3121 • www.house.gov

LCMS Representatives

- Dave Reichert (R-WA-08) www.reichert.house.gov
- John Shimkus (R-IL-19) www.shimkus.house.gov
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Brief Notes

- The pro-life movement is picking up steam across the nation, raising hope that as more Americans push for abortion restrictions, federal policy will inevitably follow. Read the story at www.cbn.com.
- Like the U.S., Europe faces rising health care costs due, in part, to an aging population. But unlike the centralization at the heart of America's new health reform law, European reformers are reversing course toward decentralized health care, increased competition and increased consumer choice. Learn more at <http://online.wsj.com>.
- Palliative care is slowly catching on. Unlike hospice care, intended for patients with six months or less to live, palliative care can be given along with curative care for the seriously ill. The benefits reported are reduced patient medical costs and increased patient wellbeing. Expect palliative care growth in coming years in doctors' offices and community settings. For more information, read www.kaiserhealthnews.org.
- London's High Court ruled a Christian couple cannot be foster parents because they will not endorse homosexuality. According to a Christian legal group, British authorities said "children risk being infected by Christian moral beliefs." Read the story at www.telegraph.co.uk. A gay, atheist media personality warned that the couple are victims of a liberal "tyrannous new morality." Read www.lifesitenews.com.
- A Nobel-prize-winning economist says elective abortion and infanticide of girls has caused a shortage of women and ominous "youth bulges" of young unmarried men in some Asian nations. In the past, similar circumstances in other countries were connected to instability, violent wars and revolutions. Read www.newsweek.com.
- A new survey released by the National Center for Health Statistics reveals over half of American teens between the ages of 15 and 17 have never had any sexual contact. This flies in the face of increasing efforts to force graphic sex education on young children and teens, as well as federal cuts to abstinence education programs in recent years. Read further at www.onenewsnow.com.

Sources: aolnews.com, cbn.com, Congress.org, Govtrack.us, Kaiser Family Foundation, LifeNews.com, LifeSiteNews, Lummis.house.gov, Newsweek, OneNewsNow.com, Roll Call, The Hill, The Telegraph, U.S. Department of Veterans Affairs, Wall Street Journal, Washington Examiner

How to Subscribe

The Lutheran Church—Missouri Synod recently launched a new website and will soon transition to a new e-News system.

To continue receiving *Mercy Notes*, or to subscribe, go to www.lcms.org by May 27 and create a myLCMS account by clicking "Register" in the top right corner of the homepage. Once your account is confirmed, log in, click the "my e-Newsletters" tab and select your subscriptions.

Note that once you sign up on the new site you may receive two e-mails for each newsletter to which you subscribe until the transition is complete.

If you have any questions regarding your account, or other items related to the new LCMS website, please contact the LCMS Church Information Center at InfoCenter@lcms.org or 888-843-5267.

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