

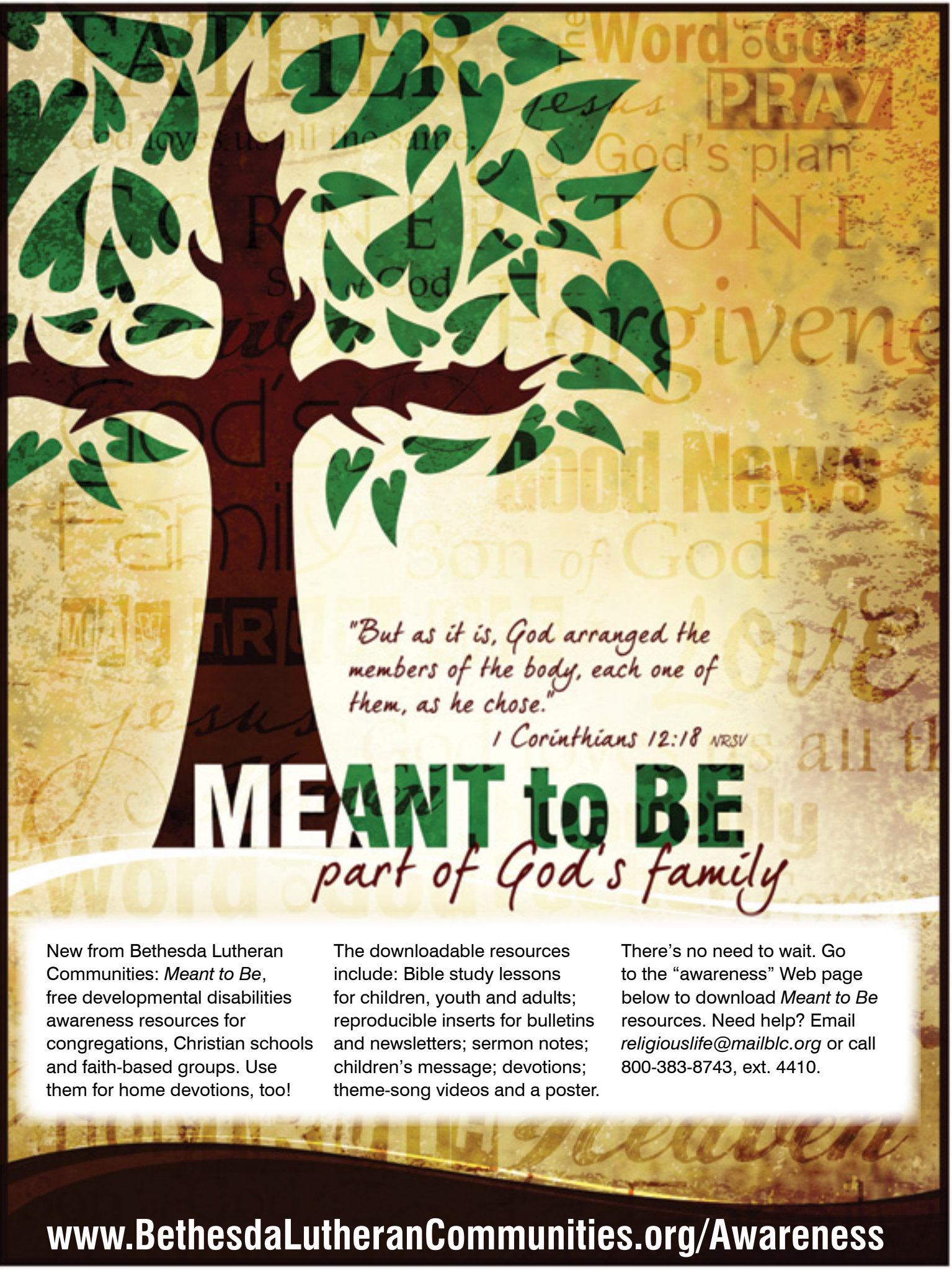


# MESSENGER



**Breaking Barriers  
to Full Inclusion**

**Breaking Down and  
Building Up in the Congregation**



*"But as it is, God arranged the members of the body, each one of them, as he chose."*

*1 Corinthians 12:18 NRSV*

# MEANT to BE

*part of God's family*

New from Bethesda Lutheran Communities: *Meant to Be*, free developmental disabilities awareness resources for congregations, Christian schools and faith-based groups. Use them for home devotions, too!

The downloadable resources include: Bible study lessons for children, youth and adults; reproducible inserts for bulletins and newsletters; sermon notes; children's message; devotions; theme-song videos and a poster.

There's no need to wait. Go to the "awareness" Web page below to download *Meant to Be* resources. Need help? Email [religiouslife@mailblc.org](mailto:religiouslife@mailblc.org) or call 800-383-8743, ext. 4410.

[www.BethesdaLutheranCommunities.org/Awareness](http://www.BethesdaLutheranCommunities.org/Awareness)

**ON THE COVER**

*Nick Jochim (left), with father, Fred, as volunteers aboard USS LST 325, a floating World War II memorial, in Evansville, Ind. Photo by LaVerne Jones.*

**INSIDE THIS ISSUE**

- 1 **Meant to Be**
- 3 **Breaking Barriers to Full Inclusion**
- 10 **News & Notes**
- 12 **Breaking Down and Building Up in the Congregation**

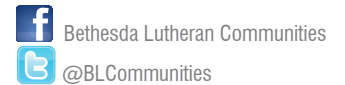
Published since 1909, *Messenger* shares stories and information about Bethesda Lutheran Communities and its person-centered, community-based mission to enhance the lives of people with intellectual and developmental disabilities through services that share the good news of Jesus Christ.

Produced by Bethesda's Marketing and Communications department, Laura Reilly, vice president. Editorial: Sue Edison-Swift, Nicholas L. Honeck, Jan Nowak. Design & Production: Terri Breese, Kristin Schneider.

© 2012 Bethesda Lutheran Communities. All rights reserved.

For permission to reprint articles, request a free subscription, and to share ideas, comments and concerns, call 800-369-4636, ext. 3817, email [pr@mailblc.org](mailto:pr@mailblc.org), or write to *Messenger*, C/O Bethesda Lutheran Communities, 600 Hoffmann Dr., Watertown, WI 53094.

Join the nationwide conversation



Check out our NEW Mobile App



**FROM THE**

**President and CEO**



*They had been saying to one another, "Who will roll away the stone for us from the entrance to the tomb? When they looked, they saw that the stone, which was very large, had already been rolled back." Mark 16:2-3 NRSV*

On that first Easter Sunday, three women made their way to the tomb to do what needed to be done: anoint the body of Jesus. It must have taken great courage for the women to set out that morning. Jesus had been crucified, a capital punishment reserved for the worst criminals. His tomb was sealed and guarded; even in death Jesus was treated like an enemy of the state.

"Who will roll away the stone?" they ask (v. 2). Who will break down the barrier keeping us from doing what needs to be done?

The risen Christ transforms the story. The stone is rolled away. Death becomes a breakable barrier, allowing the women and us to claim new, abundant and eternal life.

This issue of *Messenger* highlights some of the bureaucratic and social barriers facing people with intellectual and developmental disabilities. These barriers limit choice and community. They make it unnecessarily difficult to do what needs to be done. It takes courage and tenacity for people with disabilities, their families and other advocates to fight systemic barriers in government funding and our culture of disrespect.

As an Easter people and as a Christ-centered organization, we are called to break systemic barriers and build sustainable supports. We do this to support people with disabilities as they claim a full and abundant life. It is their right and our privilege.

*Alleluia!*

John E. Bauer, Ph.D.  
President and CEO

*Almost a quarter century after the Americans with Disabilities Act was enacted, countless barriers still exist that segregate people with disabilities. Significant roadblocks—housing, education, economic security, employment, transportation, health care and the legal system—still challenge people with intellectual and developmental disabilities.*



Jennifer Wilson's housewarming shower, given by her family and friends this past January, was a time of celebration. After a seven-year lawsuit, the 27-year-old, who has developmental disabilities, moved into her new Springfield, Ill., home and found independence that opened a new chapter of her life.

When Wilson turned 20 and graduated from high school, her parents Rick and Nancy Wilson began the search for a small group home or apartment for their daughter. They were eager to see their daughter flourish in a setting that satisfied her need for independence and safety.

"As we got older, it was harder for us to sustain the physical strength needed to give her the best care," Nancy Wilson said. "Because Jennifer uses a wheelchair, we found ourselves doing a lot of lifting. Her wheelchair did not fit through the bathroom door. Without an accessible shower, we needed to lift Jennifer in and out of the bathtub."

The Wilsons applied for a state Medicaid waiver that would enable their daughter to live in a small, community-integrated home. These homes are designed to give individuals as much independence as possible and heighten community interaction. Wilson's application was denied twice. Instead she was offered placement in a state-run institution.

"We wanted her to be in a home," Rick Wilson said. "We did not want her going into an institutional setting."

The Wilsons learned of a federal class action lawsuit, *Ligas v. Hamos*, filed against the state of Illinois in 2005. The lawsuit sought to bring the state into compliance with the 1990 federal Americans with Disabilities Act, requiring states to give an option of community-based residence to people with intellectual and developmental disabilities who want it, if it is appropriate for them and reasonable given the state's resources. The Wilsons added their daughter to the lawsuit. Seven years later, the Wilsons, along with the four others on the lawsuit, won the case.

# Breaking Barriers to Full Inclusion

*by Patricia Miller Winsten*

In January 2012, Jennifer Wilson moved into a home owned and operated by Bethesda Lutheran Communities. Now living 20 minutes from her parents' home, Wilson has her own room and a robust social life.

"Jennifer has the freedom to choose for herself what she wants to do and what makes her happy," her mother said.

## ATTITUDE BARRIERS SHAPE PUBLIC POLICY

"Societal attitudes are at the root of the many barriers Jennifer and other people with intellectual and developmental disabilities face," said the Rev. Charles E. Werth, Bethesda vice president of Religious Life and Church Relations. *(continued on next page)*

*Wilson family members, Rick (left), Jennifer, Nancy and Stephanie on the porch of Jennifer's new home.*

# About Medicaid

## Did you know?

- The federal government has one set of Medicaid policies. Each state has its own programs, rules and regulations.
- The federal government provides matching funds to each state for its Medicaid spending, ranging from 50 percent to 76 percent of every state dollar spent.
- By federal law, every person with intellectual and developmental disabilities who is eligible for Medicaid is entitled to receive support in an intermediate care facility for people with developmental disabilities (ICF-DD). An ICF-DD is either a state-run institution or an intermediate care facility operated by a private provider that offers 24-hour support.
- Services for people with disabilities, such as home and community-based supports, are funded through program waivers.
- What Medicaid waiver programs are offered and what disabilities are covered vary from state to state.
- Most states have waiting lists for services offered through waiver programs with no mandates to accommodate individuals on waiting lists within set time frames.
- To be eligible for Medicaid benefits, the recipient's total assets must be below the level set by the federal government and each state. In the states where Bethesda provides services, the allowable total asset range is between \$800 and \$2,000.



Photo by LaVerne Jones

Nick Jochim volunteers aboard the USS LST 325.

“Throughout history, people with disabilities have been devalued and dehumanized. Our language reflects society’s perceptions. The term *disabled* implies a person is inferior, broken, with little to offer. Until we put people first, and not their labels or diagnoses, we can never have fully equal civil and human rights.”

Over the past several decades, advocacy and political pressure have advanced the shift from institutionalization to home and community-based supports that empower people with disabilities to exercise the rights and freedoms of ordinary life. However, people with intellectual and developmental disabilities still remain marginalized and oppressed.

Bethesda’s Christian mission drives the organization’s commitment to person-centered supports. This commitment ensures people with intellectual and developmental disabilities are treated with dignity and respect, have real choices and lead meaningful lives as independently as possible.

### BUREAUCRATIC BARRIERS

Medicaid has become the safety net for people with intellectual and developmental disabilities. Yet the very program designed to assist people also creates barriers that can threaten quality of life for people with disabilities and their loved ones.

“The demographics of people with disabilities and the way we support them is drastically different today than it was in 1965 when Medicaid was created, but the system for funding services is essentially unchanged,” said Mark Hagen, Bethesda director of public policy. “What we have is a chaotic, incredibly inefficient system that incentivizes state waste, contributes to our skyrocketing national debt and severely limits opportunities and freedom of choice for people with disabilities.”

Virtually every family Bethesda supports, and every staff member who provides that support, can attest to the difficulty of navigating the Medicaid system. With different programs, rules and regulations in every state—and an entirely separate set of federal policies—Medicaid is confusing.

Jennifer Wilson’s parents experienced these frustrations firsthand. According to a federally-

funded survey, the state of Illinois ranked last in the nation for helping people with developmental disabilities live more independently.

“The system is fractured, disorganized and lacking,” Nancy Wilson said. “It’s difficult living in a state that does not take care of its own.”

The Wilsons have been trying for more than a year to have their daughter’s wheelchair replaced. After nine years of hard use, the wheelchair is past the point of repair.

“Medicaid officials keep asking for more paperwork,” Nancy Wilson said. “Then they always find something wrong with it and send it back to us to start all over again.”

### INSTITUTIONAL BIAS

Individuals with intellectual and developmental disabilities who are approved for Medicaid are entitled to an intermediate care facility (ICF-DD) placement at either a state-run institution or an intermediate care facility operated by a private provider. ICF-DDs are fully covered by Medicaid and acceptance is guaranteed. Home and community-based options are the designated waiver programs.

State institution placements set apart from the community pose

**The Medicaid system is biased toward state-run institutions, an outdated and the most expensive model of support. For example:**

- In Wisconsin, the average per-person cost is \$650 per day in the largest ICF-DD state-run institution.
- At Bethesda’s privately run ICF-DD in Wisconsin, the average cost to support the same person is \$375 per day.
- The cost to support the same person with Bethesda’s home and community-based services averages \$175 per day.

a barrier to full inclusion. The community integration inherent in home and community-based supports provides built-in opportunities for full inclusion. The state-run institution model is being challenged by families, advocates and the U.S. Department of Justice.

The U.S. Department of Justice has joined lawsuits or filed supporting briefs in at least 20 states to enforce community integration and the civil rights of people

### Nick Jochim

As a volunteer crewmember on the USS LST 325, a floating memorial in Evansville, Ind., Nick Jochim has had his hands on nearly every nut and bolt on the retired World War II ship. That’s what sparked the 31-year-old’s interest in welding. He hopes to begin vocational training in welding.

After an eight-year wait for a Medicaid waiver, Jochim now lives in a small group home. Bethesda provides the assistance he needs to live independently.

“We wanted to make sure Nick was well taken care of when we’re not here anymore,” said Jochim’s mother, Sherry. Without supports in place, “I was scared Nick would end up homeless. I’m now at peace because I know my son has a good home.”

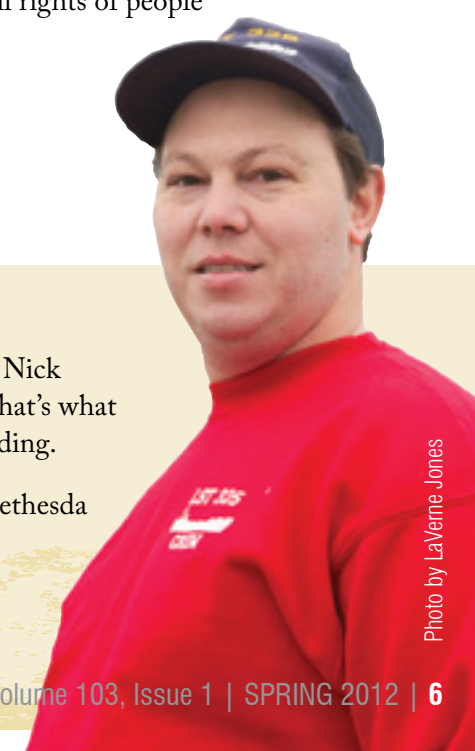


Photo by LaVerne Jones

with intellectual and developmental disabilities as outlined in the 1999 Supreme Court decision in *Olmstead v. L.C.* This decision requires states to provide services to people with disabilities in the most integrated setting appropriate to the individual.

Significant advancements in medical services and home and community-based support programs make the state-run institutional model unnecessary for providing even the highest level of support to people with intellectual and developmental disabilities. Personal care aides, accessible transportation, homemaker services, adult day programs and other supports have made it possible to develop far more independent residential alternatives. Most people with intellectual and developmental disabilities do not need—or want—institutional 24-hour skilled services.

The deinstitutionalization movement spurred by the *Olmstead* decision led to rapid expansion of home and community-based supports such as group homes and other supportive community living. In 2009, Medicaid spending for home and community-based

services was more than double that of state-run institutional support. However, funding for a strong infrastructure of home and community-based supports has not kept pace with demand.

**WAITING-LIST BARRIERS**

Many families have no choice but to accept placement in a fully funded, state-run institution. Since states are not required to fund home and community-based supports, these services are offered as optional Medicaid waiver programs that vary from state to state. States are allowed to limit eligibility and cap enrollment for home and community-based supports. This can result in lengthy waiting lists.

The number of Americans with intellectual and developmental disabilities on waiting lists for home and community-based supports has dramatically increased. A 2011 survey by The ARC suggests there are more than one million people with intellectual and developmental disabilities waiting for services that may never become available to them.

Because states are not required to offer Medicaid waiver programs, these programs are at risk when cash-strapped states cut their

budgets. When home and community-based options are reduced or eliminated, people with intellectual and developmental disabilities have fewer and more restrictive choices.

Nick Jochim was on an Indiana waiting list for eight years before he received funding to live in a home and community-based setting. The long wait for a Medicaid waiver challenged Jochim's parents.

“As Nick got older, it became more difficult to support him,” said Sherry Jochim, Nick's mother. “It was a 24-hour-a-day job that was extremely stressful.”

Several years into the waiting period, the Jochims received a call from the state, alerting them their son was number 200 on the waiting list. The state offered placement in a large state-run institution in Indianapolis. The institutional setting, along with the three-hour drive, was unacceptable to the family.

“It wasn't even a consideration for us,” said Fred Jochim, Nick's father. “We said ‘no,’ and we didn't hear back from the state for several years.”

In 2010, the state of Indiana finally gave Jochim a Medicaid waiver to

live in a community-based setting. Now 31 years old, Jochim is living a life of greater independence and personal satisfaction. He shares a home with three other men and receives supports from Bethesda that include transportation and personal assistance. This allows Jochim to live and be active in his community. His parents are thrilled to see their son thriving in his new home environment.

**POVERTY BARRIERS**

People with intellectual and developmental disabilities and their families often face staggering financial burdens. The 2011 ARC survey reports 79 percent of people with intellectual and developmental disabilities live in poverty.

The income restrictions for Medicaid and Supplemental Security Income limit people to a maximum of \$2,000 in assets. This restricts people with disabilities who want to save money for tuition, vocational training or, in Jennifer Wilson's case, a new wheelchair.

According to The ARC survey, 85 percent of adults with intellectual and developmental disabilities are not employed. Those who are employed usually make minimum wage. The majority of adults with disabilities report they cannot get the assistance they need to secure employment.

The survey further shows that because of the complexity of restrictions, most people with intellectual and developmental disabilities are living at home with their families. More than three-quarters of these families report they cannot access in-home supports and community services.

Eight in 10 families report they don't have enough money to cover the needed expenses for in-home support. Because public assistance is so difficult to access, families face significant financial, physical and emotional stress.

William Kerr, 23, lives in Denver with his mother, Dottie Kerr. He has been on a waiting list for home and community-based support since he was 16. This past January, the Kerrs were told the wait would be at least another 15 years.

“I asked them what would happen to my son if I were in a car accident or died tomorrow. Would he get housing?” said Dottie Kerr, a single parent. “They said he'd move to the top of the list. He'd get housing in six to 12 months. In the meantime, he'd be homeless.”

Kerr ultimately went to court to get her son covered through Supplemental Security Income and Medicaid. They continue to wait for a waiver that will allow William Kerr to live in a community-based setting. Living with his mother while he waits, Kerr participates in Bethesda's Supportive Living Services day program and is studying computer graphics at a nearby community college.

During his first year, a Bethesda direct support professional accompanied Kerr on the bus and to class. Now Kerr is confident enough to take public transportation and get to classes on his own. With Bethesda's support, Kerr is involved in numerous activities, including volunteering at a local soup kitchen.

“It's not easy. I have to be on call for Will, 24/7,” Kerr's mother said. A registered nurse, Dottie Kerr works

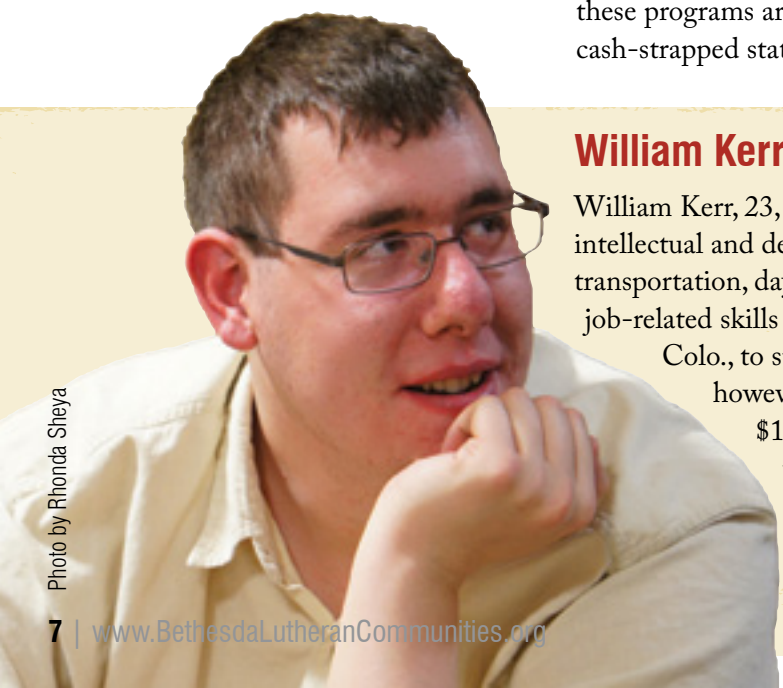
**Action Alert**

Bethesda urges Congress to enact the “Achieving a Better Life Experience” (ABLE) Act. The ABLE Act would allow people with intellectual and developmental disabilities to have tax-exempt savings of up to \$100,000 to promote independence and quality of life. These savings could be used for disability-related expenses such as housing, supportive services, employment support, transportation and health care. Funds in an ABLE account would not jeopardize Medicaid eligibility. Contact your legislators to let them know you support the ABLE Act. <http://bit.ly/AdvocateABLE>

in home health care because it gives her enough flexibility to check in on her son during the day. “Without Bethesda's support, eventually, I would have had to stop working. Bethesda has been a life saver.”

Dottie Kerr's worry is well-founded. Parents, siblings and other family members generally serve as the primary source of support for people with disabilities. According to The ARC survey, in one of five families, someone needed to quit their job to be at home with a family member who has a disability.

The state of Colorado recently cut the reimbursement rate to providers of programs similar to the one Kerr attends. “The state is cutting its budget on the backs of people with disabilities,” Dottie Kerr said. “Where will people like my son go without these programs?”



**William Kerr**

William Kerr, 23, exemplifies the employment dilemma many people with intellectual and developmental disabilities face. Through Bethesda, Kerr has transportation, day programming and other supports that allow him to develop job-related skills and attend Arapahoe Community College, Littleton, Colo., to study graphic arts. Kerr will risk losing his medicaid benefits, however, once he becomes employed. “If he makes more than \$1,000 a month, Will would lose all benefits, including the transportation he needs to get to work,” explained his mother, Dottie Kerr. “His medications alone last year were more than \$50,000. Thank heavens Medicaid paid for them. Will needs to stay in the system, so he's forced to walk a very fine balancing line with employment.”

Photo by Rhonda Sheya

## MEDICAID BARRIER NEEDS BREAKING

“Our nation is facing unprecedented state and federal budget deficits,” said Dr. John E. Bauer, Bethesda president and CEO. “We cannot maintain existing spending standards and expect the system to remain solvent. It is, without question, unsustainable.”

States are responding to budget deficits by reducing funding for intellectual and developmental disabilities support services, denying or limiting eligibility, making late payments and giving ever-lower reimbursements to providers. Nonprofit providers like Bethesda are left to fill the gaps.

In Illinois, for example, Bethesda lost \$660,000 in 2011, the difference between the actual cost of services and what the state reimbursed. The state currently owes Bethesda nearly \$2.25 million for services already provided.

“Essentially, Bethesda is giving the state a loan” said Mark Hagen, Bethesda’s public policy director. “But most of our expenses are for payroll. We cannot give our employees an IOU.”

Adding to the crisis of shrinking federal and state resources is the burgeoning population of families with aging parents who are providing primary support to their adult children with disabilities. Nationally, more than 700,000 people with intellectual or developmental disabilities are living with family aged 60 years or older. The ARC survey revealed almost 60 percent of family members providing support at home are between the ages of 51 to 79. “Where will the individuals with intellectual and developmental disabilities live and who will support them when their family members are no longer able to do so?” the report asks.

## ADVOCATING FOR CHANGE

“An unprecedented challenge creates an unprecedented opportunity for change,” Dr. Bauer said. “Now is the time to enact significant system reform that reduces costly inefficiencies, abolishes the institutional bias, ensures long-term sustainability, and allows people to obtain the services they want in the setting of their choice.”

Bethesda Lutheran Communities is actively advocating for reversing the Medicaid entitlement and waiver options (see box below.) It contends home and community-based supports should be the entitlement and placement in an ICF-DD should be the waiver.

“It’s a common-sense solution,” Dr. Bauer said. “This change reflects the preferred choice of most people with intellectual and developmental disabilities. It builds in opportunities for community involvement and offers quality, person-centered supports at a lower cost.”

Bethesda takes a non-partisan approach in its advocacy. “This isn’t a Republican or Democrat issue,” Dr. Bauer said. “It’s a moral issue. Together, we can break down the barriers that deny the civil and human rights of people with intellectual and developmental disabilities.”

*Patricia Miller Winsten, Milwaukee, Wis., is a freelance writer, editor and owner of Miller Winsten Communications.*

# NEWS & Notes



*Raul Andrade (left), area director; Jim Klein; Hope Contrucci, mission advancement director; and Dr. Jack Preus, executive vice president of Mission Advancement.*

## Donation Delivers Two Vans

A generous donation from the Lloyd E. and Elizabeth H. Klein Family Foundation made it possible for Bethesda Lutheran Communities to purchase two wheelchair lift-equipped vans for use in southern California.

“The new vans provide the people living in two homes with safe, reliable and comfortable transportation,” said Stephanie Licht, qualified developmental disability manager. “The size of the van allows for all the people living and working in the home to access the community together.”

Jim and Debbie Klein, representatives of the family foundation, presented the check to Bethesda in February. “I’m just the manager fulfilling the legacy of my parents and God,” Jim Klein said.

*To connect with one of Bethesda’s mission advancement directors and learn about transformational, planned and estate gifts, call 800-383-8743, ext. 4420.*

*New home in New Palestine, Ind. (above)*

## New Homes Support Independence, Community

Two new homes in Indiana illustrate Bethesda Lutheran Communities’ commitment to provide living options that enhance independence and community connection.

Bethesda is supporting four people in New Palestine, Ind., who live in a new home custom designed and built by Lancia Homes, Fort Wayne, Ind. The home offers maximum independence for people with intellectual and developmental disabilities who have mobility and medical challenges.

“Lancia Homes was invaluable throughout the process,” said Monica Griffin, Bethesda area director. “They sought input from people we support, found the site and did a lot of leg work.”

The four-bedroom, ranch-style home features a ceiling-mounted

track lift system, which allows individuals with mobility challenges to access areas of the home with minimal staff assistance. Additionally, the home is equipped with accessible showers, a front-loading washer and dryer, and a garage that accommodates a van with a wheelchair lift.

In Fort Wayne, Bethesda supports three individuals with intellectual and developmental disabilities who live in a ranch-style home. The three-bedroom, open-concept house features a sizable backyard in a small, quiet neighborhood. The home is located a short distance from a shopping district.

“The location offers great access to the community,” said Gillian Frazier, Bethesda area director. “The people who live in the home are very independent, so it is a great fit.”



*Jessica Reynolds (left), Stephen Murray, Brenda Twitty and Shay Beatson on the patio at their new home in New Palestine, Ind.*

## Reverse the entitlement

For years, Bethesda and the Lutheran Services in America Disability Network have taken the position that the Medicaid system of entitlement and waiver must be reversed. Currently, the Medicaid *entitlement* for people with intellectual and developmental disabilities is ICF-DD support. They must seek a *waiver* to access home and community-based support. People with intellectual and developmental disabilities should be *entitled* to home and community-based services and, as needed, seek a *waiver* to live in an ICF-DD.

By reversing the system, significant cost savings for the state and federal government will be realized. Medicaid will become an effective means of support, allowing people to live in the setting of their choice and fully participate in their communities.



**Camperships Needed**

A gift of \$500 to the Bethesda Campership Fund helps an adult with disabilities to experience a one-week camp session. Gifts of any amount are welcome and will be applied to camper costs other than transportation to and from camp. Gifts may be directed “where needed most” or designated for a specific camp.

 Contribute to the Bethesda Campership Fund at [www.BethesdaLutheranCommunities.org/Camperships](http://www.BethesdaLutheranCommunities.org/Camperships).

**Green Bay Thrift Shop Re-Opens**

Bethesda Lutheran Communities re-opened its Green Bay, Wis., thrift shop in early April. The shop, which originally opened in 1976, is one of the first Bethesda Thrift Shops in northeastern Wisconsin.

“In the fall of 2010 Bethesda had to make a financial decision to close the Green Bay location,” said John Nickels, executive director of Bethesda Enterprises. “With a strong response from the Green Bay community, careful negotiations and an innovative business model, we are excited about re-opening.”

The 10,000 square-foot thrift shop will offer a wide selection of gently used merchandise, including clothing, household goods, furniture, books, linens, jewelry, electrical items, antiques and collectibles. The store will introduce single price points for clothing, including \$1.99 for all adult T-shirts, blouses and sweaters; 99 cents for infant and toddler tops and bottoms, and boy and girl shirts, tees and sweaters. In addition, the store will feature new furniture that includes mattresses, sofas, chairs, dressers and dining sets.

 To find a Bethesda Thrift Shop location near you, visit [www.BethesdaLutheranCommunities.org/ThriftShops](http://www.BethesdaLutheranCommunities.org/ThriftShops).

**Memorial Gifts Remember Beloved Daughter**

A little gazebo on her daughter’s farm in northern Illinois inspired Adeline Ward’s latest donation to Bethesda Lutheran Communities. The gift, offered in memory of Ward’s daughter Rebecca, is designated for Bethesda’s camp ministries.

“Becky would invite friends and family over,” Ward said. “She’d roast hot dogs and we’d eat in the gazebo, enjoying the outdoors.”

Years ago, Ward and her late husband, Johnny, became donors after visiting Bethesda’s Watertown campus. “We fell in love with Bethesda. It’s important that everyone has a home,” Adeline Ward said.

After her father died, Rebecca Ward began to donate to Bethesda. “She had a soft, open heart for people with developmental disabilities,” her mother said.

Adeline Ward has a long-standing practice of giving memorial gifts designated for Bethesda. “I want to introduce people to Bethesda and give them hope,” she said. “I acknowledge their loved one is at home in heaven and note that the memorial gift will help other members of God’s family find loving homes at Bethesda.”


Ward’s daughter died three years ago after a battle with cancer, so the



Adeline Ward with a portrait of her daughter, Rebecca Ward.

donations she gives in Rebecca’s memory are especially poignant.

“I thank God for all the years we had,” she said. “Becky was an angel and we had a good life together.”

 To give a gift to Bethesda in someone’s memory or honor, donate online at [www.BethesdaLutheranCommunities.org/Give](http://www.BethesdaLutheranCommunities.org/Give), call 800-383-8743, ext. 4420, or email [development@mailblc.org](mailto:development@mailblc.org).

For everything there is a season, and a time for every matter under heaven: a time to break down, and a time to build up.

—Ecclesiastes 3:1, 3b NRSV

**Breaking Down and Building Up**  
*in the Congregation*

by the Rev. Charles E. Werth

Thankfully, a great deal of breaking down occurred in church buildings during the last 30 years. With awareness, planning, effort and a blueprint, many accessibility barriers—which had prevented full participation by people with physical disabilities—were removed. Sadly, barriers of another kind remain in place within the church—barriers which prevent the full inclusion of people with intellectual and developmental disabilities, as well as to their families and others who support them.

More often than not, these barriers result from a lack of understanding on the part of well-meaning people of God who have no significant disabilities. The barriers to full inclusion exist because they haven’t been identified as barriers. Once aware of the problem, planning can begin to both break down barriers and build up people and congregations. The goal is to transform congregations and other faith communities into places of belonging and becoming for people with intellectual and developmental disabilities.

**Break down the culture of disrespect**

Throughout history people with intellectual and developmental disabilities have been hidden from sight, including within the family of the church. Even today, people with intellectual and developmental disabilities are often devalued, considered inferior and seen as broken. People with intellectual and developmental disabilities and their families have been discouraged from active participation in congregations with comments like: “We’re glad you’re here, but we’re not equipped to deal with your son.” “Maybe you would be more comfortable in the cry room.”

The words used when speaking about people with disabilities reveal and reinforce a common lack of understanding. For example, when the local traffic reporter announces there is a “disabled” car in the right lane of the expressway, it conjures up the image of a powerless vehicle. A person with a disability is not powerless. A person who has a disability is not a disabled person. In spite of a body part that works differently or a particular medical diagnosis, a person with a disability or multiple disabilities possesses talents, skills and abilities that are disregarded by careless use of language. Handicapped, disabled, special needs, mentally retarded, autistic, learning disabled, non-verbal, crippled, wheelchair bound, brain damaged: these words and phrases define a person not by their abilities but by a disability or a medical condition.

The campaign to abolish the “R-word” conducted by *Spread the Word to End the Word* has heightened awareness that people with intellectual and developmental disabilities are surrounded by a culture of disrespect.

**Build up sanctuaries, congregations**

Christ’s great commission to “make disciples of all nations” (Matthew 28:19) most assuredly includes people with intellectual and developmental disabilities. Without adopting a paternalistic or patronizing attitude toward people with

*People First Language* by Kathie Snow is an indispensable primer for any congregation or group. Find it at [www.disabilityisnatural.com](http://www.disabilityisnatural.com).

To connect with a Bethesda ministry consultant, email [religiouslife@mailblc.org](mailto:religiouslife@mailblc.org) or call 800-383-8743, ext. 4410.

disabilities, the church is called to be a sanctuary from the caustic cruelty

of our culture of disrespect. After all, isn't that how we refer to the worship space within a church building: the sanctuary? It is time for congregations to be built up as sanctuaries to educate, enlighten and empower the membership to respect all of God's gifts to the church, including people with disabilities.

The department of Religious Life of Bethesda Lutheran Communities exists to equip the church to minister *with* people who have intellectual and developmental disabilities. Bethesda's 21 ministry consultants equip congregations across the country to build up ministries so people with intellectual and developmental disabilities are enabled to become all God intends them to be, here and in the world to come. Resource materials from the Bethesda Institute and other sources support these efforts.

More than 300 BethesdaNetwork congregations—any Christian congregation that provides spiritual supports in partnership with Bethesda Lutheran Communities—actively seek the full inclusion of people of differing disabilities. By 2015, Bethesda envisions a BethesdaNetwork of more than 700 congregations.

Building a new way of ministry requires a planning process and a blueprint. Bethesda ministry consultants use four steps when equipping congregations to fully include people with intellectual and developmental disabilities in the life of the congregation: **inform, incorporate, integrate** and **involve**.

**STEP 1. INFORM**

The first step in the process is to gather information.

- Performing a cost/benefit analysis may help motivate a congregation to build up a disability ministry. Bethesda's "Outreach Calculator" (see box, p. 14) can help demonstrate the potential for congregational growth when it builds up a disability ministry.
- Biennially, Bethesda's Religious Life department produces disability awareness resources. The 2012 materials, *Meant to Be*, are available online ([BethesdaLutheranCommunities.org/Awareness](http://BethesdaLutheranCommunities.org/Awareness)). The free *Meant to Be* resources include sermon notes, devotions, children's message and Bible

studies for all ages from early childhood through adulthood. *Meant to Be* offers a four-part Bible study series useful for congregational leaders considering disability ministry.

- Once a congregation has taken the step of informing itself about ministry with people who have disabilities, the next step is planning the entry points for meaningful inclusion. Bethesda's *Building a Developmental Disability Ministry* is a valuable resource, especially with the guidance of a Bethesda ministry consultant. Find the free, online resource at [www.BethesdaLutheranCommunities.org/FaithResources](http://www.BethesdaLutheranCommunities.org/FaithResources).

With information gathered, the congregation can proceed to the second step, incorporation.

**STEP 2. INCORPORATE**

*Incorporation*—including people with developmental disabilities in the congregation—involves addressing some basic questions.

- Who are the providers that operate community-integrated living opportunities in the congregation's neighborhood? Some simple research will help develop a strategy for contacting those providers, building relationships and extending invitations. Bethesda ministry consultants are prepared to guide a congregation through this process.
- How might the congregation create multiple spaces scattered *throughout* the nave (church) for people who use a wheelchairs?
- Which congregation members will be recruited and equipped to serve as *worship companions* for people with disabilities and the people who may accompany them?
- How will members be prepared to accept a behavior that may occasionally be exhibited by a worshipper with a disability?

Congregations, following the building up blueprint, move from *incorporation* to *integration*.

**STEP 3. INTEGRATE**

The move from incorporation to integration—fully including people with disabilities in the faith community—is a subtle and important step.

The congregation then must consider worship from the point of view of people with developmental disabilities:

"I have limited control of my hand and arm movements, and I am expected to open my hymnal." "Hymnals are open, but I don't read." "The congregation is asked to rise, which I am only able to do in spirit." "An atmosphere of quiet is expected, but I cannot control the sounds I make."

Worship companions from the congregation, prepared through a process using Bethesda personnel and resources, can develop creative responses to each of these considerations. At this point in the planning process, a congregation has the opportunity to proceed in two directions, either in phases or simultaneously.

Since breaking in to a congregation can be daunting to a person with a disability, some prefer the option of a dedicated ministry (worship and education experiences designed specifically for people with disabilities). Properly planned, including adequate volunteer assistance, this option is sometimes a preferred entry point for people with disabilities.

Some people with disabilities who are active members of their congregation also participate in a monthly dedicated worship event designed for people with disabilities. "I love church on Sunday," a young woman said, "but sometimes I just want to be with people like me."

Bethesda has resources to support both the dedicated and the integrated options in congregations. With the ultimate goal of full inclusion in the life of the congregation, it might be wise for a congregation to include both options in its blueprint for building up. First inaugurate a dedicated worship and study ministry that *integrates* people with disabilities into the congregation as it builds up the congregation toward full *involvement*.

**STEP 4. INVOLVE**

A fully inclusive congregation is one in which all people are *involved* to the extent they desire, and are embraced as full partners in congregational life. Inclusive involvement respects the choices of people with disabilities to lead independent lives, to experience the freedom to reach their God-given potential, to be included and involved in a congregation as equal partners in worship and faith-formation activities.

What does *involvement* look like? People with disabilities seamlessly worship with the whole

congregation. They participate in age-appropriate groups and activities. They use their God-given talents, including singing, playing hand bells, greeting, ushering and assisting in a Sunday school class.

Bethesda's fundamental goal is to create an environment within the congregation that reflects mutual respect among people with a variety of abilities, who learn from each other as equals in God's creation. Arbitrary distinctions disappear, barriers have been broken down, and the church has built-up fully inclusive ministries.

*The Rev. Charles E. Werth is vice president of Religious Life and Church Relations.*

Congregational Outreach Calculator	
It is estimated that 1.5 to 2.5 percent of the U.S. population— 4.6 to 7.7 million people—have intellectual and other developmental disabilities.	
1. Multiply the population of your community by .02 (two percent).  _____ x .02 = A Population	A. Estimated number of people with developmental disabilities in our community  _____ A
Because of negative experiences in congregations and other reasons, it is estimated that 85 percent of people with developmental disabilities, along with their families, are "de-churched," they no longer attend worship services.	
2. Multiply the number in box A by .85 (eighty-five percent).  _____ x .85 = B A	B. Estimated number of people who may especially welcome the opportunity to connect with our congregation  _____ B
People with developmental disabilities often attend church with others, including friends, family and the staff people who support them.	
3. Multiply the number in box B by 2.  _____ x 2 = C B	C. Estimated number of people waiting for the welcoming outreach of our congregation  _____ C




**Bethesda**  
 LUTHERAN COMMUNITIES  
 600 Hoffmann Drive  
 Watertown, WI 53094-6204

Non-Profit  
 U.S. Postage  
**PAID**  
 Bethesda Lutheran  
 Communities

Electronic Service Requested

## How can I use my smart phone to enhance lives?



### We have an app for that!

- Find our 21 Bethesda Thrift Shop locations for donating, volunteering and shopping.
- Locate and contact Bethesda regional offices for available resources.
- Learn by following BethesdaVoices tweets.
- Follow us on Facebook and YouTube.
- Receive timely alerts concerning the field of disabilities and how you can make a difference.
- Donate any amount to make a meaningful contribution to enhance the lives of people with intellectual and developmental disabilities.

**iEnhanceLives**

DOWNLOAD NOW!

