



Quarterly

Spring 2011

Published by the Ohio Developmental Disabilities Council to bring disability issues and accomplishments to the attention of Ohioans.

ODDC Releases Family Impact Study Findings

This edition of the DD Quarterly features Caring for Children with Disabilities in Ohio: The Impact on Families, a study designed to assess the effects of caring for children with disabilities on families.

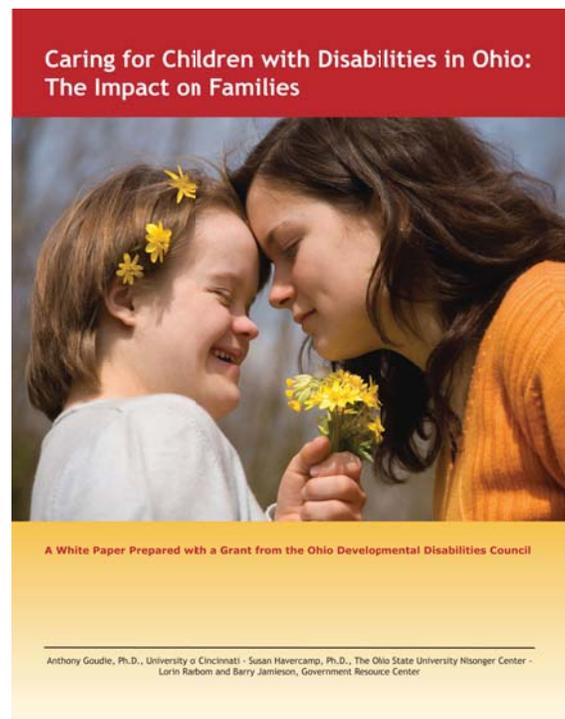
Raising a child with a disability is often a positive life experience. Many families who care for a child with a disability develop a closeness and experience interpersonal growth leading to a cohesive family unit. Families caring for a child with a disability report that, "The presence of my child is very uplifting. Because of my child, I have many unexpected pleasures. My child is the reason I am a more responsible person."

While the benefits of raising a child with a disability should not be overlooked or underestimated when assessing the impact of disability on a family, findings from a study funded by ODDC show that Ohio families raising children with disabilities are more likely to experience economic hardship and emotional stress compared to families caring for children without disabilities. Furthermore, implementing programs designed to reduce stressors for families who have children with disabilities may result in increases in annual family income, local and state business activity, tax revenues and work productivity.

The study, *Caring for Children with Disabilities in Ohio: The Impact on Families* (Ohio Impact Study), is the first known of its kind in Ohio and shows that families caring for children with disabilities face particular challenges

not encountered by families raising children without disabilities.

Carolyn Knight, executive director of ODDC said, "Although families encounter many gratifying experiences, the Ohio Impact Study focuses on the hardships and barriers a family faces when they raise a child with a disability. We finally can definitively tell legislators and other policy makers what the implications are for families and communities and that there are measurable costs – economic costs and social costs – that impact families caring for children with disabilities and the communities where they live."



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ODDC Mission

It is the mission of the Ohio Developmental Disabilities Council to create change that improves independence, productivity and inclusion in community life for people with disabilities and their families.

Research and Findings

To estimate the economic, social and emotional impact on families raising children with disabilities, the Ohio Impact Study research team analyzed results of several national and Ohio health care and community surveys; reviewed Medicaid claims data; and conducted focus groups of families with children with disabilities.

The comprehensive analysis of data from the surveys and the information gathered at the focus groups showed that families caring for children with disabilities are more likely to have:

- less self-reported annual family income;
- greater personal financial strife;
- less employment security;
- elevated levels of emotional stress; and
- greater use of health services by their children.

These factors, according to the study's authors, contribute to high rates of chronic stress for families caring for children with disabilities.

Implications

The study identified a gap in the level of emotional and social support for families with children with disabilities. The authors emphasized the need for a better family support system in Ohio, noting that there is room for improvement in helping families who care for children with disabilities to lessen levels of stress. (For a more complete listing of the study's findings see pages 4-5.)

The Ohio Impact Study was prepared by a research team including Lorin Ranbom and Barry Jamieson from the Ohio Colleges of Medicine Government Resource Center, Susan Havercamp from Nisonger Center at The Ohio State University and Anthony Goudie from the University of Cincinnati, Cincinnati Children's Hospital Medical Center.

To read the full study, go to <http://ddc.ohio.gov/Pub/OHFamImpStudyWhitePaper-FINAL.pdf>. ■

Thoughts on the Ohio Impact Study

Nestor Melnyk, former chair of ODDC's Children's Issues Committee was instrumental in the conceptualization of the Ohio Impact Study. His comments below reflect his understanding of the far-reaching implications of the study on families and their communities.

Most of us whose lives are impacted by a person with a developmental disability are aware of the many effects on our lives. Documenting some of these in a quantitative way is important not only for credibility, but also to measure the effects on our larger society and economy.

Many "outsiders" focus on issues with tangible costs and benefits and how these affect the issues. Two interrelated costs addressed in the study occur when a highly educated and trained person leaves the workforce to care for a person with a developmental disability: loss of income, which reduces economic activity and decreases tax bases; and loss of qualified workers, which creates a strain on workforce development and business activities. The study can therefore show that these are not just family issues, but issues that affect our overall society and economy in Ohio.

The ongoing purpose of the Ohio Impact Study is to use the information to show how services to people with disabilities and their families are a long-term investment that benefit our larger society and economy in very real, measurable and tangible ways. This evidence can help create positive change that can greatly improve the lives of people with disabilities and their families while also benefitting the communities where they live. ■

Chairman's Message



Peter Keiser
Chairman of ODDC

Council's Children's Issues Committee funded and oversaw the development of *Caring for Children with Disabilities in Ohio: The Impact on Families* (Ohio Impact Study). Their support of this study is another example of Council's leadership in the disability arena for issues important to people with disabilities and their families.

Reading the Ohio Impact Study made me reflect on and speculate about the effects my disability had on my family. My parents made a

conscious decision to develop a positive attitude about my disability and to treat me like my siblings and to set high expectations for all of us. My family always expressed pride in my accomplishments as a student and as a professional.

Times were very different in the 1950s when I was a child. Most families relied on a single income and mothers usually did not work outside the home (at least not among our neighbors and friends) until their children were older. My stay-at-home mother acknowledged that my disability helped her "find her voice" and become a leading advocate for children with disabilities. She was a founding member of United Cerebral Palsy (UCP) of Cincinnati and over the course of her involvement with the group, she was president of the board and volunteered as the executive director. Her countless hours and years of service to the organization was time away from her family but she was determined to assure that other families who had children with cerebral palsy had support and information.

My father was chief patent counsel for a major corporation, so while the cost of my therapies and other needs did not have a significant financial impact on my family, I am sure there were some other hardships. I think the more significant impact on my family, though, was the time my mother spent away from the family driving me to various medical or therapy appointments and the time she devoted to her advocacy activities. I'm sure my siblings were disappointed and maybe even resented that our mother missed some of their sporting events and other important school functions because of her volunteer obligations.

Although the effects on siblings of children with disabilities were not covered in the Ohio Impact Study, this issue will be included in the study's next phase funded by ODDC. Based on my own family's experiences and similar experiences that families encounter today, I believe this will be an important issue to expand upon. ■



Improving the lives of
Ohioans with disabilities

The Ohio Developmental Disabilities Council is a group of 35 people, appointed by the governor, who plan and advocate for Ohioans with disabilities. ODDC receives federal funds and distributes those funds by awarding grants for projects and activities that create visions, influence public policy, pilot new approaches, empower individuals and families, and advocate system change.

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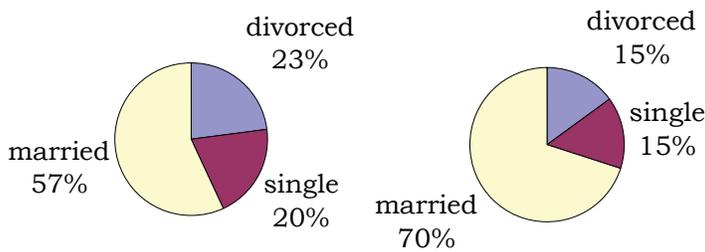
Ohio Impact Study Findings

The ODDC funded study, *Caring for Children with Disabilities in Ohio: The Impact on Families* (Ohio Impact Study), identified differences between families raising a child with a disability compared to families raising a child without a disability. Having a child with a disability impacts a family in a multitude of ways including financially, socially and emotionally. Major findings of the Ohio Impact Study are highlighted in this article.

Marital Status

The Ohio Impact Study found, through a review of national disability-related research, that raising a child with a disability causes marital strain, increasing the probability of divorce or separation. Graph 1 shows the divorce rate for Ohio families caring for a child with a disability is higher than the divorce rate for families caring for a child without a disability.

Graph 1: Marital status of families caring for a child with and without disabilities.



Caring for a child with disabilities

Caring for a child without disabilities

Income

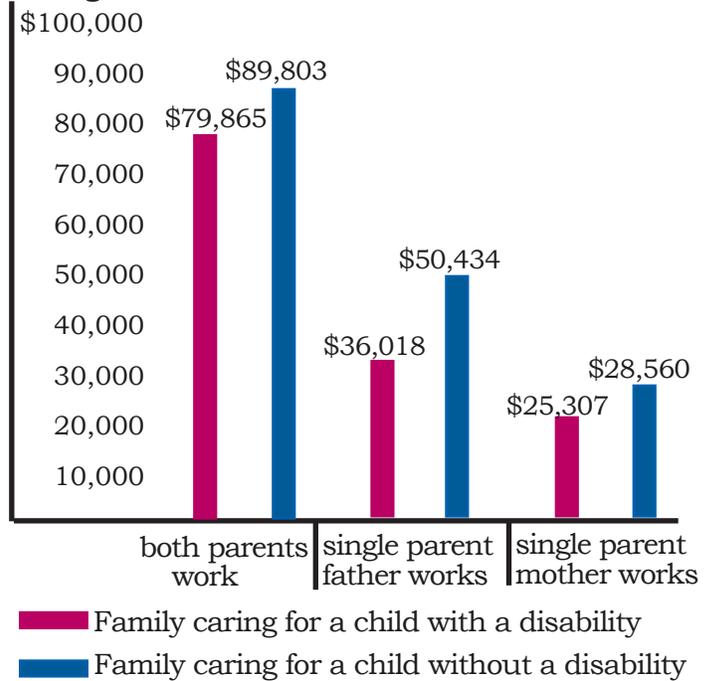
The study found that families caring for children with disabilities have lower mean incomes compared to families caring for children who do not have disabilities. This statistic remained constant even when data sets were matched. For example, when analyzing data from matched families who are couples with only the father in the workforce, the average income of those families raising a child with a disability was \$64,000 compared to the \$84,000 average income of those families that did not include a child with a disability.

According to the study, mothers of children with disabilities are less likely to work outside of the home. Over half (52%) of the Ohio households that did not include children with disabilities and were headed by a couple, had

both parents in the workforce. This compares with only 33% of households that included a child with a disability and headed by a couple with both parents in the workforce.

Graph 2 shows that working families raising children with disabilities earn less income than working families who are raising children without disabilities.

Graph 2: Difference in average income for families caring for children with and without disabilities.



Families participating in the focus groups identified some logical reasons for the large discrepancy in the average family income for families raising children with disabilities:

- parents work fewer hours because they need to provide and coordinate care for their child with a disability.
- parents keep or take lower paying jobs closer to their home so they can better respond to care giving needs.
- parents take lower paying jobs because of health insurance reasons.
- parents are fatigued and are less available to work due to physical and emotional exhaustion related to caring for their child with a disability.

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Family Finances

Ohio families caring for children with disabilities experience financial hardship. Twenty percent of Ohio families report spending more than \$1,000 per year for medical bills for their child with a disability.

The study found that over half (52%) of the families caring for a child with a disability have difficulty paying their medical bills – compared to only 32% of families with children without disabilities. For families including a child with a disability:

- 50% reported being unable to pay for basic necessities such as food, heat or rent.
- 71% reported using most of their savings to pay medical bills.
- 43% reported having large credit card bills or taking a loan to cover medical expenses.

Health Care

The study found that all of Ohio’s children have relatively good access to health care. Children with disabilities use primary health care services, including mental health and therapy services more than children without disabilities. Children with disabilities visit hospital emergency rooms more frequently than children without disabilities and hospital admissions are higher for children with disabilities.

Families coordinate these health care services which requires time, effort and resources. A high percent (28%) of families caring for their child with a disability report spending 11 hours or more per week coordinating or providing health care for their child. The study also found:

- 26% of families caring for a child with a disability cut back employment hours to meet the health care needs of their child.
- 32% of families caring for a child with a disability had a family member stop working to care for a child with a disability.

Emotional

Worrying about finances, health care issues and the general well-being of their child increases emotional stress levels for some families raising children with disabilities. These families are overwhelmed by stress and according to the study, have very little emotional support. The study found that 21% of the families raising a child with a disability had no one they could turn to for emotional support.

Communities

The study estimates that there is about a 480 million dollar income gap in Ohio between families who care for children with disabilities compared to those families who care for children without disabilities. This impacts local communities by having less business activity, decreased tax revenues and a diminished work force.

Summary

The study shows that raising a child with a disability has a significant impact on families. Families are affected by an increased demand on their time, reduced earning potential, and increased financial expenditures, all resulting in increased emotional stress.

These results clearly show a need for improved family support in Ohio. ■

Other Ohio Impact Study Findings

	Family raising a child	
	with a disability	without a disability
Average annual out-of-pocket costs for health care	\$535	\$192
Percent of children accessing mental health services	38.0%	13.0%

Insights from the Family Focus Groups

by Susan Havercamp, Nisonger Center

The intention of the Ohio Impact Study was to shed light on the effects of disability on families. The research team's objective in this project was to better understand the financial, social, and emotional impact of disability on the family.

Staff at Nisonger Center facilitated family focus groups to assure the family voice was included in the study. The research team recognized the value of listening to and learning from Ohio families to develop a clearer understanding of how raising a child with a disability impacted their lives.

Focus Groups

Three focus groups were conducted and included parents, grandparents, and siblings of children and adults with disabilities and special health care needs. The focus groups were structured to capture the impact of the child's disability on family life. Efforts were made to recruit people who could speak to the unique challenges that are presented in early childhood, school-age, transition age and adulthood. Focus groups, held in urban and rural areas, explored the economic, social and emotional impact of the disability itself and the impact of navigating the social services system, waiting for services and functioning without needed supports and services. Family members spoke openly about the unique challenges they are presented in caring for children with disabilities and about how their children enrich their lives.

... and I will say that my oldest two children are more compassionate than most children of their years, and have a lot of loving, and they've opened up a whole new world. They've been more human, as you would say.

Quote from a mother at a focus group discussing her typically developing children

I had to quit my job, so that my wife can have her career...because she will go further in her career than I will. So, I have a master's degree and I'm delivering newspapers so that I'm available to take Robert to school because he can't ride the bus right now because there are behavior issues.

And the school will call me by one o'clock on any given afternoon to say, "His top has popped, there's nothing more we can do for him." And I will pick him up....

Quote from a father at a focus group

Nisonger staff believe that presenting the stories behind the statistics helps policymakers understand why, for example, families of kids with disabilities report personal financial strife. We included family member quotes from these focus groups along-side each of our major statistical findings in the Ohio Impact Study.

Next Steps

Families participating in the focus groups provided valuable input and helped shape the outcomes of the study. ODDC, policymakers and others are encouraged to use the information from the focus groups and the data analyses to improve family support systems and services in Ohio. ■

They say children with autism need to have their intervention services as soon as possible. However, I've been on a waiting list and I can't get help. I'm in one of those that, you know, I can't get it because I'm not poor enough. I can't get it because I can't afford it.

Quote from a mother at a focus group

Value of Focus Groups

The family perspectives helped to illustrate the statistics from surveys and Medicaid claims data and to educate the public and policy makers toward finding opportunities for improving systems and services for families.



Family Focus Group Stories

Two family members who participated in the Ohio Impact Study focus groups agreed to share their stories detailing how raising their children with disabilities affected their lives.

Shelley's Story

I enjoyed participating in the family focus group for the Ohio Impact Study. Sharing my story and listening to other families discuss their issues helped me realize that many other families are going through similar situations and that we are not the only ones dealing with issues regarding our children. The knowledge that other families have and shared at the focus group was invaluable to me.

My husband and I have four children ages 14 to 21. Our two older children are in college and our two younger children are enrolled in special education programs in the public schools in our community.

As parents, we have the expectation and the hope that our children's lives will follow a typical developmental path. It was overwhelming when faced with the reality that this may not happen for all our children. This feeling of being overwhelmed persists as we encounter new and existing challenges as our children grow and develop.

Having children with disabilities has impacted our family in a variety of ways. Our older children developed an increased sensitivity and genuine caring for people with disabilities. As parents, our marriage has become stronger as we bond together to address our children's needs. However, there are still stressors we face daily.

Financial

Even though we have good insurance, our children's medications can exceed \$1,000 a month. In addition, when the children were younger we paid out-of-pocket for occupational therapy, physical therapy and speech therapy and we currently pay for educational tutors at a rate of \$40 per session. We also pay for many new, innovative therapeutic treatments not covered by insurance. We have made considerable sacrifices and concessions that

most families in our community take for granted so we could fund the services and therapies necessary for our children.

Siblings

Over the years, we intentionally tried to assure our older children received the same financial and emotional support from us that our younger sons received. Even with that, they have encountered issues. For example, at times our older children hesitated to invite their friends to our home because they were afraid of the potential embarrassment caused by their brothers' behaviors. And even though there is only an 18 month age difference, they do not share common friends and interests. Life has been different for our two older children as they deal with stressors that are unique to siblings of brothers with disabilities.

Stressors

Everyday a new challenge may arise – and you never know what it is going to be. In addition to the “everyday” stressors, it is extremely stressful for me to think about my sons' futures. Will they be employed? Will they have insurance? Will they be able to live independently? Will they have emotional support? Will they be content?

Even though we face emotional stress and are being pushed financially, we consider our sons to be gifts who have taught our whole family countless lessons about what is truly important in life. ■

Marie's Story

Shortly after giving birth to Peter, a beautiful baby boy, he was swept away to the neonatal intensive care unit (NICU) because of breathing difficulties. We were relieved and grateful when told he was going to be fine. Then the pediatrician told us that our son had Down syndrome and he would stay in the NICU until he could eat and breath on his own. For my husband and me, the issue wasn't having a son with Down syndrome – it was the fact that he was in the NICU and could not come home

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right away. Little did I know this was just the beginning of what life would hold for my little guy and our family.

Peter had major surgery when he was five days old and was in the intensive care unit for six weeks. I had crash courses about nasogastric feeding tubes and colostomy bags and how much care was involved with these medically necessary items. I also learned more about Down syndrome and how caring for a child with this diagnosis would affect our lives. And several years later when our third child, Patrick, was diagnosed with Autism, we encountered additional challenges.

Employment Barriers

Since Peter's birth, I have been unable to hold a full-time job. For the past 20 years I worked around my husband's schedule and found a number of part-time jobs and self-employment to help defray some of the costs of Peter's medical supplies which continue to be our biggest concern. The supplies are not cheap and he will need them for the rest of his life.

Also, when my husband was younger and wanted to change jobs, he was unable to because most companies had pre-existing condition clauses in their health insurance coverage and we didn't want to risk losing our health care coverage.

Emotional Effects

Throughout the years, isolation, depression, loneliness and exhaustion have been a constant battle and I haven't known where to turn. I've wondered if these feelings will ever go away, but they never do. And with each transition our children go through, we go through all of these feelings again. For example, now our son Peter is an adult and I feel like I'm starting all over because the adult service system has different rules, its own maze of finding services and no mandatory services.

Most parents look forward to their sons or daughters graduating from high school, going on to college, finding a job and entering into a relationship with someone special. This is not



Marie's sons, from left to right Patrick, Tom and Peter.

to say that my sons will not be able to do these things but they will come in a different form - just like most everything in their lives.

Service System Frustrations

Over the years many wonderful people have come in and out of our life. Our son Patrick had ten speech pathologists in 12 years. He recently had an outstanding one who understood him, always had a smile on her face and was getting him to use a communication device. So for once, we were finally moving in the right direction and getting everyone on the same page, with the hope of seeing significant changes.

Well, it wasn't meant to last. The therapist recently informed me she is moving out of state. I had hopes that Patrick, with help from the therapist, would be able to tell us what he wants, let us know when he is sick or show us where something hurts. All I want is for him to be like other teenagers. And I don't want to once again break in a new therapist. I'm weary...how many times are we going to cross this bridge?

I look around and I realize I'm not alone. I know a younger mom who has a four-year-old son with Down syndrome. I've been there and know her pain. I feel a need to be strong for her but I can't because I've lost hope once again. I want my son to talk and to do this he needs appropriate and consistent services. I dream of this miracle every day, but every day, it's just another hurdle. ■

Cincinnati UCEDD Promotes Health Awareness

by Tena Benson, University of Cincinnati UCEDD, Division of Developmental and Behavioral Pediatrics, Cincinnati Children's Hospital Medical Center

National Women's Health Week encourages women to take charge of their own health and learn ways to improve their physical and mental health and lower their risks of certain health problems. During May 8 - 14, 2011, the University of Cincinnati (UC) University Center for Excellence in Developmental Disabilities (UCEDD) at Cincinnati Children's Hospital Medical Center Division of Developmental and Behavioral Pediatrics will join with the U.S. Department of Health and Human Services Office on Women's Health to celebrate National Women's Health Week 2011.



This year the UC UCEDD will offer two Women's Health Week programs specially designed for women in the Greater Cincinnati area with developmental disabilities. These programs will offer training in safety, healthy eating and being active and fit. Local experts from the Cincinnati Police Department, Nutrition Council of Greater Cincinnati and Cincinnati Recreation Commission-Therapeutic Recreation will speak. This year's programs, by popular demand, will be:

- May 6: Third Annual "Spring into Action 3" for women ages 16-29
- May 13: "Be Safe. Be Smart. Be Strong." for women over age 30

In 2009 and 2010, the UC UCEDD Women's Health Week day-long programs attracted over 175 women with developmental disabilities.

Learn more about Women's Health Week 2011 at www.womenshealth.gov/whw/.

Men's Health Day

We didn't forget the men! On December 3, 2010, the first "Ultimate Men's Health Day" was held and over 50 men with developmental disabilities attended to hear experts from Hamilton County Developmental Disabilities Services, the TALL Institute and Cincinnati Recreation Commission-Therapeutic Recreation lead sessions on feeling good, being safe and being active.

Feedback from self-advocates was positive and included comments such as, "The program will help me take better care of myself," "I had so much fun," and "I wish we could do this once a month." They also liked "getting to know people" and "getting to talk with people."

We would also like to thank our community partners for their great support of the Women's Health Week and Men's Health Day programs. For more information about the programs, contact Tena Benson (513) 636-4333 or by email at tena.benson@cchmc.org. ■



Participants at last year's health awareness days at the University of Cincinnati UCEDD

The Women's Health Week 2011 programs are supported in part by funding for Women's Health Week from the Ohio Department of Health, Office of Healthy Ohio, Bureau of Health Promotion and Risk Reduction, Violence and Injury Prevention Program. This project is administered by HEALTH-UC and the University of Cincinnati AHEC Program.

Project Manager Reflects on Study's Findings

Barry Jamieson, from the Government Resource Center, was the project manager for the Ohio Impact Study. The DD Quarterly asked Jamieson several questions about the study, the findings and the implications.

DD Quarterly: In the report you comment that this is the first known study of its kind in Ohio. Why is this study unique?

Jamieson: This study is unique in a couple ways. First, this is a mixed-methods study. That means that the multidisciplinary research team used both quantitative and qualitative methods to measure the impact on families caring for children with disabilities. We did not want to simply crunch numbers and provide a general overview to these questions. We also wanted to provide a human face behind the data through the voices of our focus groups participants. We think both methods combined tell a compelling story of the impact on families. Second, we used data from several different sources, including the American Community Survey, the Ohio Family Health Survey, the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs, Medicaid claims data and focus groups to collectively paint the picture of how families are impacted.

DD Quarterly: What challenges did you encounter?

Jamieson: The study was meant to focus on the impact to Ohio families. With some of the data, the Ohio sample was too small, so we had to rely on national information to describe the impact. In the focus groups, we had a hard time finding a good cross section of families (e.g. race, poverty level) that have children with disabilities. Although we were appreciative of the input provided by families in the focus groups, we wanted to hear from families who had not received much in the way of services and supports. It was difficult for us to recruit family members from underrepresented groups.

DD Quarterly: How did the information from the family focus groups help shape the study's results?

Jamieson: We tried to integrate family responses from the focus groups with our data analysis. For example, our report details the extent of income differences between families with children with disabilities and those with children without disabilities. In the focus groups we asked families specifically how they are impacted financially. Hearing their compelling responses about financial hardships related to caring for their child with a disability made us more aware as a research team what the story was behind the statistics. Because of this, every data table we provided in our final research report included a relevant quote from the focus groups to remind the reader of the real world impact on families.

DD Quarterly: What key finding from the study surprised you the most?

Jamieson: I was most surprised by the extent of the income differences identified between families caring for children with and without disabilities. For example, in two-parent families with only a father in the workforce, there was approximately a \$20,000 income difference regardless of the demographic and labor force participation variations. The bottom line is that families who care for children with disabilities have lower incomes compared to seemingly identical families who care for children without disabilities. This income loss is just one of many stressors on the family. After taking into account the added physical and emotional stress placed on families, the combined impact on families can be overwhelming.



*Barry Jamieson,
project manager
Ohio Impact Study*

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DD Quarterly: In your research, how did health care utilization impact families?

Jamieson: We wanted to look at the impact of health care utilization on families because we realize that families spend a lot of time coordinating and participating in getting health care for their children. We note that 28% of all families with a child with a disability spend over 11 hours a week coordinating health care for their child. Over one-half of these families had a parent who had to cut back on working hours or stop work altogether to provide and coordinate health care for their child. Our research showed that for families with a child with Medicaid coverage there are a lot of potentially unnecessary emergency room visits or admissions to the hospital that could be avoided with a better care management system in place.

DD Quarterly: The data used in the study were based on years prior to the current economic downturn. Do you think the results would be even more dramatic than what you reported if you used data from the past 18 months during the recession?

Jamieson: I do not believe the income or job participation differential between families will increase with the recession: both types of families will be negatively hit by the downturn. That said, since families are already taking a severe economic and emotional toll by caring for their child with a disability, I am concerned about the ability of these families to sustain further economic and emotional stress.

DD Quarterly: What do you think is the value of the study and how can the results be used?

Jamieson: In the field of developmental disabilities, it is often difficult to describe objectively how consumers, families or providers are affected by various changes that are occurring in their environment. This study provides concrete data on how these families are impacted and the results suggest that there is a lot of room for improvement in alleviating stress on families.

DD Quarterly: Are there plans to conduct follow-up studies based on the results of the study?

Jamieson: We are pleased that ODDC will be funding the Government Resource Center for a second phase of the study. One topic included in Phase II is to study the impact on siblings in families who are caring for a child with disability. Our initial study looked at the overall impact to families but really didn't detail how siblings are affected. Another topic we are examining in Phase II is determining what services are most helpful to families. We will conduct surveys of state program directors, as well as program experts and families of children with disabilities to try to rank what services are most effective and most in need. ■

The Government Resource Center

The Government Resource Center (GRC) is a collaborative effort of the Council of Medical School Deans of the seven colleges of medicine in Ohio. The GRC is housed administratively within the Office of Health Sciences at The Ohio State University.

GRC's primary objective is to assemble the expertise of the medical colleges and related health and social sciences programs in the 13 four-year public universities in Ohio to provide clinical and health sciences consulting services to state and local governments that either purchase or manage health care services. All information regarding the GRC including obtaining the "Caring for Children with Disabilities in Ohio: Impact on Families" report, can be found at www.grc.osu.edu. ■



Self Advocates Meet with Their Legislators

More than 400 self advocates, families, providers, policymakers and other stakeholders from throughout Ohio attended the Legislative Advocacy Day at the Statehouse on April 14, 2011. The event, "Moving Forward: The Horizon for the Disability Community," was sponsored by the Ohio Developmental Disabilities Network.

The mission of the self advocates was to educate policymakers about current issues related to necessary supports for community access and inclusion and about how a lack of these services affects people with disabilities.

Several keynote speakers, including Senator Peggy Lehner of the 6th Senate District and Representative Ted Celeste of the 24th



John Hannah

House District, encouraged self advocates to tell their stories to their legislators. Other speakers at the event included John Martin, director, Ohio Department of Developmental

Disabilities; Robert Milliken, ODDC member and John Hannah, self advocate. Director Martin discussed budget issues while Milliken and Hannah inspired self advocates with rousing speeches.

After the presentations, event organizers scheduled 275 appointments for self advocates and their legislators. Eric Marshall, a self advocate from Shelby County planned to tell



Eric Marshall

his legislator about a letter he wrote to President Obama regarding the need for people with disabilities to be employed. Marshall said, "People with disabilities need to work so they can live in and be a part of their community." He continued, "I am going to also tell my legislator that young people with disabilities should not be forced to live in nursing homes."

The Ohio Developmental Disabilities Network includes ODDC, Ohio Legal Rights Service and the two University Centers of Excellence in Developmental Disabilities: The Ohio State University Nisonger Center and the University of Cincinnati Children's Hospital. This year's event was also supported by the Ohio Olmstead Task Force, the Autism Society of Ohio and the Autism Society of America, Central Ohio Chapter. ■

Tell ODDC Your Thoughts about its 5-Year Plan

ODDC wants your input on its 2012-2016 State Plan. The 5-year plan includes Council's funding priorities and identifies projects it plans to support in this funding cycle.

The funding priorities in the plan were developed by Council members and staff with input from stakeholders throughout the state during the past two years.

ODDC values input from people with disabilities, their family members and their providers. People are encouraged to review the plan and submit comments.

The State Plan is available online at <http://ddc.ohio.gov/2012-2016%20State%20Plan%20-%20Final.pdf>. Submit your comments before June 10, 2011 by email to Fatica.Ayers@dodd.ohio.gov or call ODDC at (614) 644-5543.

If you want the State Plan in an accessible format or if you have questions, contact Tammy Waller at Tammy.Waller@dodd.ohio.gov or call her at (614) 466-5205. ■

Meet ODDC's Newest Members

Three Ohioans received appointments to ODDC by the governor. Peter Keiser, chair of ODDC, said, "I am impressed with the credentials and the wealth of experiences each new member brings to Council. These three members, like all new appointees, bring new perspectives. The blending of these perspectives, skills and diverse backgrounds is what makes Ohio's Council so unique."

The three new members replace Shelley Papenfuse, Curt Wellman and Nestor Melnyk whose terms expired at the end of 2010.



Jacob King III

Jacob lives in Gahanna and is the Chief Financial Officer of The National Center for Urban Solutions. He also hosts a weekly radio show, "One Million Motivated Minds."

He has a Master's Degree in Business from Keller Graduate School of

Management. Jacob's background and work experience includes helping people with personal finance and job readiness, teaching and consulting. He also participates in several activities that promote inclusion of people with disabilities in community activities.

"I have first-hand knowledge of the challenges people with disabilities face. I was in a car accident several years ago resulting in a spinal cord injury," said Jacob. He maintains a strong belief that most people with disabilities can be self-sufficient with the proper support and assistance.

He is honored to be on Council, and is interested in helping with the policy, finance and leadership committees. ■



Diane Cox

Diane lives in Avon with her husband Matthew, their son Benjamin (7) and daughter Emily (3).

Diane provides full-time care for Benjamin who has undiagnosed global developmental disabilities and currently receives physical, occupational,

speech, swimming, feeding and other therapies from a variety of sources, both public and private.

Speculating about her role on Council, Diane said, "I look forward to learning more about and becoming involved in the Children's Issues Committee and would like to bridge the gap between families of children with disabilities and available services and programs." ■



Denise Gilmore

Denise lives in Dayton and is currently working on her Doctor of Ministry.

She worked at the Jewish Vocational Service where she helped people with disabilities earn their General Educational Development (GED) diploma or prepared

them for entrance to college or trade school. Denise also worked in the secondary education field helping youth make positive life choices.

Denise said, "I first learned about ODDC through participation on the Triple Jeopardy project in Dayton. I was so impressed with that project and want to be a part of other exciting Council projects over the next several years."

It is her desire to be an articulate voice for those whose voice is not heard. ■

Apply to Become an ODDC Member

ODDC is seeking applicants for membership terms beginning in October 2011. ODDC membership must comply with categories listed in the federal Developmental Disabilities Act. Openings this year will be for the following categories:

- one individual with a developmental disability, and
- one immediate relative or guardian of an adult with a mentally impairing developmental disability who cannot advocate for himself/herself.

All candidates for ODDC membership should have experience serving on committees, boards or organizations. Experience with persons with developmental disabilities is especially relevant. Applicants should have first-hand knowledge about developmental disabilities in Ohio.

It is very important that applicants have time to attend six meetings per year and serve on at least two committees. Each meeting of ODDC occurs over a two-day period.

Governor Kasich will appoint members for three-year terms beginning October 1, 2011 and ending September 30, 2014. Applications must be returned to ODDC by May 31, 2011.



Carolyn Knight, executive director, and Peter Keiser, Chair, at the April ODDC meeting.

Apply for ODDC Membership

- on ODDC's website at: www.ddc.ohio.gov
- by email: Carla.Sykes@dodd.ohio.gov
- in person or by mail:
ODDC
899 East Broad St., Suite 203
Columbus, Ohio 43205
- by phone: (614) 466-5205 or
(800) 766-7426

If you leave a message, please spell your name and provide your phone number and address, including zip code.

Application Deadline
May 31, 2011

Benefits of Being a Member

Serving as a member of ODDC provides the opportunity to work in a collaborative manner with state and federal policy makers, state and local providers and individuals with developmental disabilities and their family members. ODDC advocates to improve the system of supports and services for individuals with developmental disabilities and their families, and it conducts grant activities for the same purpose.

About ODDC

ODDC is a planning and advocacy body committed to community inclusion for people with developmental disabilities.

It is the mission of ODDC to create change that improves independence, productivity and inclusion for people with developmental disabilities and their families in community life.

ODDC consists of at least 28 members who are people with developmental disabilities, parents and guardians of people with developmental disabilities, representatives from concerned state agencies, and nonprofit organizations and local agencies providing services to people with developmental disabilities. ■

News from Ohio Legal Rights Service (LRS)

Balancing Formal and Natural Supports Keeps People with Disabilities Living in the Community

by Kristen Henry and Kevin Truitt, Staff Attorneys

Medicaid waivers allow people with disabilities to receive services while living in the community, an option which is overwhelmingly more desired than expensive institutional settings, such as nursing homes. However, the Medicaid waiver system places considerable reliance on “natural supports” – family and friends who provide substantial amounts of care for people with disabilities when paid providers are not present.

The Ohio Impact Study found that family caregivers often experience elevated stress levels. When the amount of natural support required is excessive, stress levels increase and the health and well-being of these family members and friends, and ultimately the person they care for, often suffer as a consequence of this heavy burden.

The Ohio Department of Developmental Disabilities is proposing in the 2012 and 2013 state budget bill to keep waiver expenditures “flat” in order to keep its budget balanced. The Department hopes this can be accomplished by families sharing services, reducing service requests and/or implementing cost-saving services as submitted to the Center for Medicaid Services, such as remote monitoring. The Department plans to work with families and self-advocates to achieve a 3% utilization reduction in waiver services.

What can you do?

Without the appropriate balance of formal and natural supports, a person with a disability risks being placed in an institution. Although the situation is dire for many families, there are encouraging instances where families receive greater formal levels of support, alleviating some of the stress and strain on their lives. Decisions made by Medicaid or agencies that administer Medicaid waivers about the amount of natural support a family member must provide are

subject to Medicaid’s hearing process. This process gives individuals the opportunity to show that the agency is requiring the provision of too much natural support. Individuals who believe they are not receiving enough services because their family members are required to provide too much natural support can request assistance from LRS. LRS can advocate for the person with a disability, and in some cases provide representation at a Medicaid hearing. For more information, see the LRS website at www.olrs.ohio.gov or call Intake at (800) 282-9181 or TTY (800) 858-3542. ■

LRS Advocates for Individualized, Balanced Supports for Families

LRS represented a person with a developmental disability who was erroneously disenrolled from the Transitions MRDD waiver but who failed to appeal the decision timely. Because of the nature of this specific waiver, he permanently lost his waiver slot and remained eligible only for the Individual Options (IO) waiver, which has a long waiting list in his county. The loss of his waiver meant his mother assumed almost complete responsibility for caring for him and his extensive needs, causing a serious impact on her health. LRS advocated for an emergency IO waiver, which is appropriate when a primary caregiver is unable to continue to provide previous levels of support and substantial harm could result to the person with a disability.

LRS represented two children who experience potentially fatal seizures throughout the night. Each child had several hours of night nursing services, but their mother had to be awake all night with her children when a nurse was not present, causing severe exhaustion. The family

article continues on page 16



Improving the lives of Ohioans with disabilities



OHIO LEGAL RIGHTS SERVICE

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DD Quarterly can be viewed at www.ddc.ohio.gov or at www.olrs.ohio.gov

To share your comments or suggestions, contact Tom Hemmert at LRS:

Voice: (614) 466-7264
(800) 282-9181
(Toll free in Ohio)

TTY: (614) 728-2553
(800) 858-3542
(Toll free in Ohio)

Fax: (614) 644-1888

Email: newsletter@olrs.state.oh.us

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Network Partners on Facebook



The Ohio Developmental Disabilities (DD) Network partners now have a Facebook page. The Network uses the page to post events, activities, announcements and achievements.

To keep updated and informed about the work of the Network, go to www.facebook.com/ohioddnetwork and "Like" the Network page.

Ohio DD Network partners include ODDC, Ohio Legal Rights Service, and the University Centers for Excellence in Developmental Disabilities at The Ohio State University (Nisonger Center) and at the University of Cincinnati.

The Ohio DD Network Facebook page is an ongoing collaboration of the Network partners.

LRS Advocates (continued)

was able to obtain additional night nursing services to allow the mother more time to rest and sleep.

LRS represented two children who have a rare disorder that requires round-the-clock nursing or aide care. Their father, a single parent who works outside the home over 50 hours a week, was required to provide so many hours of natural support to each child that he was unable to sleep, take care of the home, or be a parent to the clients' teenage sister. Their father developed serious medical problems due to the excessive hours of natural support he provided, but has managed to keep his sons at home. LRS has filed an administrative appeal seeking 24-hour care for both children. ■

