

# The Arc of Minnesota's Legislative Planning Day for the 2005 Legislative Session

On September 9th at Arlington Hills Library on the East Side of Saint Paul, The Arc of Minnesota and its volunteers, local Arc chapters staff and interested parents gathered for four hours to identify the top issues that will need to be worked on in the next legislative session.

Anne Henry of the Minnesota Disability Law Center began the day by reviewing previous sessions and outlined some pieces of what to expect in 2005. "The \$4.5 billion dollar deficit created an earthquake for people with disabilities. The Governor has been very clear on his 'no new tax' pledge," said Henry.

Questions entertaining the idea of a lawsuit response to the recent Consumer Directed Community Supports (CDCS) cuts were thrown in Henry's direction. "Right now I don't think a lawsuit is going to get relief, but we need to go through legislative education to assist with relief. I really want everyone to understand that it starts with the legislature and the Minnesota Department of Human Services Administration."

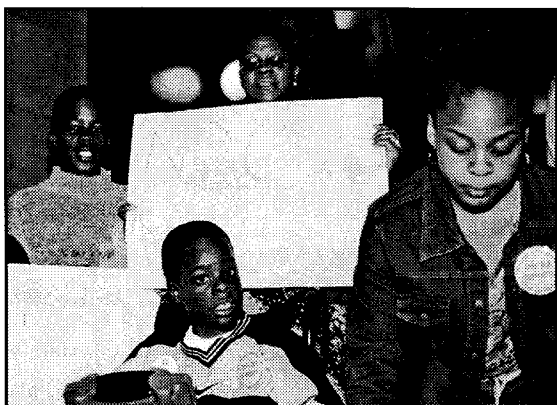
One of the highlights from Henry's overview was the need for clear concrete data. "It's been a difficult time trying to gather information from the Minnesota Department of Human Services and trying to attain raw data that we can bring to the legislature." (If you would like to view a summary of last year's legislative session, go to [www.arcgreatrivers.com](http://www.arcgreatrivers.com) and click on Legislative Center.)

The group then rolled up their sleeves and reviewed last year's priorities and began adding a variety of issues that will need to be tackled. Some of those issues included CDCS, reductions to Parental Fees, development of other consumer directed alternatives, commitments to quality assurance, plus many others.

Although there was not time to define specific strategies, some discussion was geared towards ways to educate the community and legislators. Town meetings were just one of the ideas discussed as a possible strategy for getting Arc's issues across to the media and legislators. Look for upcoming dates for town meetings in early 2005 in your area.

Additional topics were developed that may not be legislative, however, these issues will be released in upcoming publications from Arc Great Rivers and The Arc of Minnesota.

Also look for a detailed legislative priority update in the upcoming editions of *The Connection* and stay tuned to [www.arcgreatrivers.com](http://www.arcgreatrivers.com) or call your local Arc office.



*The 2003 legislative session shocked people with developmental disabilities and their families...however many rallied by going to the Capitol. This year will be no different...we will need everyone to speak up to our state policy leaders.*

## Who is Arc Great Rivers?

Arc Great Rivers is a non-profit organization that provides advocacy and support for people with developmental disabilities and their families. Arc informs people of their choices and helps them gain experiences and breakdown barriers. People with developmental disabilities should be respected and included in our society. Parents are not alone and are welcome to join us to connect with others.

How does Arc support families and build communities? Arc's wide range of services include:

- **Networking and Support Groups**—For parents, siblings, and guardians. We currently offer Latino and Hmong support.
- **Family Education**—Training and skill building workshops are offered on a regular basis.
- **Pilot Parents**—A one to one peer support program for parents of children with disabilities or special needs.
- **Individual and System Advocacy**—Assistance to find needed supports and services and problem resolution. Training and support to become involved in system design and change.

## Arc Great Rivers' Future Society...Building Generations of Support

What do you think about when you hear about Arc Great Rivers? Do you think about what services it provides for you today? More importantly, do you think how it can help future generations navigate the complexities of life with a member who has a disability? Arc asks you to think about the future. In consideration of that future, please think about giving a current of future gift in support of Arc. For detailed information on your options on how to contribute to Arc Great Rivers' future, contact Marianne Reich at 763-783-4763 or visit [www.arcgreatrivers.com](http://www.arcgreatrivers.com).

### Arc thanks the following donors (cont.)

Pentair Foundation • Reiman, Edie  
Rupert, Richard & Elisabeth in memory of  
Mary T. Rupert  
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South Anoka County Chapter  
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## Sign up for Arc Great Rivers Public Policy E-list

The 2005 legislative session is right around the corner. Please e-mail or call Jacki McCormack at [jmmccormack@arcgreativers.com](mailto:jmmccormack@arcgreativers.com) or 651-523-0876. PLEASE NOTE that Jacki may no longer have you on her list due to an address book failure. Please send her an e-mail to be re-added to the list. Thanks and we apologize for any inconvenience.

## "Driven by Love" Arc ASK Event

Hosted by The Arc of MN &  
Arc Great Rivers

November 4 • 12:00-1:00pm

Four Points Sheridan on Hamline & 94 in St. Paul

This is an opportunity to get to know more about Arc, what we do and how you can help the Arc legacy continue on for future generations. We're looking for table captains to invite people they know to participate in this Arc fundraiser. You will receive a free lunch.

Call Diane Peters at 763-783-4764 if you'd like to participate.



# Consumer Directed Community Supports (CDCS): A Moving Target of Issues

*Editor's Note: In the last edition of "The Connection" you met Isaiah Fisher who was and still is dealing with the difficulties of navigating the rivers of CDCS amendment changes. The following letter was recently shared with Arc Great Rivers and also sent to several government agencies including the Minnesota Department of Human Services. This parent has asked to keep her name anonymous. Arc would like to thank this family for sharing their story.*

*Moreover, the struggle to understand the budget methodology and appeals rights of individuals and their families has been a difficult task and continues to be a work in progress. We encourage you to contact your local Arc office to gain up to date information on CDCS or continue to check our website at [www.arcgreativers.com](http://www.arcgreativers.com).*

Imagine that about 15 years ago your five-year-old child, niece, nephew or grandchild started to experience headaches and vomiting, and after misdiagnoses by physicians, an eye doctor suspects a brain tumor. Imagine following along as your child has surgery during which her optic nerve is nicked, leaving one eye permanently legally blind. Imagine that following surgery this innocent child has a stroke; therefore, your loved one has to relearn how to roll over, eat, get dressed, walk and talk—to the best of her ability – and still has problems with muscle strength and balance. Also imagine that the location of the partially removed tumor leaves permanent disabilities such as precocious puberty, short term memory loss, inability to regulate body temperature or to decipher when she's had enough food to eat. Furthermore, imagine that when shunts are placed in her head, she develops infections that affect her IQ (68) —forever. In addition, imagine that following a year of chemotherapy; a life-long side effect involves peripheral neuropathy. Can you further imagine that your child has since lived with some level of pain every day for 15 years, but with help from family, friends, medical, education and human services professionals, you manage to help her maintain a happy, relatively healthy quality of life while living at home? If you can imagine just one-half of this vulnerable 20 year-old's many challenges, **perhaps you understand why I must protest the proposed reduction of her waived services from a per diem of \$77.25 (\$29,000 yr) to \$48.24 (\$17,600 yr).**

We applied for waived services through Ramsey County shortly before her 18th birthday. The waiver has helped her to safely live as independent a life as possible for her. Following are activities (related to her disabilities and included in her Personal Support Plan) that the waiver helps make possible when she is not at her school transition program.

- She lives at home and we provide healthy, specific foods that don't complicate weight, gall stones & acid reflux symptoms—*medical & ongoing health needs in her individual service plan (ISP).*
- She participates in semi-supervised exercise (she's over weight but has lost five pounds and increased muscle strength on her left [stroke] side and balance since receiving her Y membership). This is the most cost-effective supervised program and is only available through membership and is prescribed by her physician and not covered by her health insurance. **I protest dropping the cost of \$52 month or \$624 year—health & safety outcomes in ISP.**

- She volunteers under direct supervision—*vulnerability & community integration in ISP.*
- She is working on maintaining part-time—*supported employment with natural supports.*
- She participates in Special Olympics—*community integration and physical outcomes in plan.*
- She swims at Courage Center's therapy pool—*health and physical outcomes in plan.*
- She has learned valuable navigation, decision-making, memory cue, and money management skills through trips to the library, making purchases at grocery and retail stores, and recreational events. **I protest dropping "ALL" entertainment activities which would preclude seeing educational movies at the science museum, plays at InterAct, History Theatre and other venues that help develop critical thinking skills, appropriate social behavior and community awareness-I request that \$400 a year remain in the budget for recreation that is demonstrably educational and fits into the outcomes of her plan—community integration and intellectual functioning in her ISP.**
- Finally, she has aspirations of being an artist and the skills she's learning not only help with her personal goals, but with fine motor skills and emotional stability—*medical and vocational outcomes in her ISP.*

Since she is vulnerable and cannot drive due to partial blindness and intellectual functioning, most of these activities wouldn't be possible without the services of informal support persons, and their transportation costs, because I am her principal caregiver. I work 35 hours a week and cannot always be present to help with basic needs such as putting on a bra, washing her hair, waking her up at night to use the bathroom, driving her to activities or making a meal.

In addition, the waiver provides respite time for me while she attends a weeklong session at Camp Friendship once a year, or on occasional evenings when she is with a personal support attendant, or during infrequent overnights.

You can do the math:

- \$17,600 would barely cover costs for transportation and mandated Adult Day Care or Day Training Habilitation or DT&H in combination with supported employment when she completes school in May, 2005. Typical costs are \$66 per day plus transportation (\$16,104 + \$1,220).
- It would mean severe cuts in personal assistance that allow disability, health-related, learning, social and daily living activities.
- It would end the modifications we've been able to make that allow her to perform simple tasks which we take for granted, like taking a shower without assistance.
- It would not enable us to hire a job coach for her supported employment.
- It would severely limit her choices in regard to self-direction. Unless I drove her everywhere, paid for exercise, all community integration activities and never was apart from her overnight, the options that have contributed to her quality of life will not exist with the proposed cut. Without regular supervised exercise activities, her health would deteriorate causing the government to pay more in medical costs in the long run.
- It could mean that she would have to be placed in an institution or group home at a cost to the taxpayers of at least \$59,500 if not more in

## Mission Statement

All people with Developmental Disabilities  
enjoy the communities in which they  
live, learn, work and play.

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order to receive mandated and quality of life supports since I cannot afford to cover all of her activities with my income.

This young woman, who almost every day announces, "Today has been the best day of my life," would suffer even more from the hand that life has given her. **Therefore, I protest the cuts.**

Cordially,

A Parent

## Roommate Wanted

Roommate needed (male, age 30-60) in fun Shoreview home for our 48 year-old son who has Down Syndrome. Call Phyllis Pearson at 651-633-1774.

### **Staff at Suburban**

Marianne Reich  
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Child Advocacy

Scott Schifsky  
Adult Advocate & Communications Coordinator

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Secretary

Lina Marin  
Latino Outreach

Deb Kohlhardt  
Advocate & Family Services Specialist

Steve Tollerud  
Accountant/Family Support Specialist

### **Staff at St. Paul**

Jacki McCormack  
Child Advocacy & Public Policy Director

(Mindy) Choua Thao  
Hmong Outreach Worker

Luann Palmer  
Adult Service Coordinator  
e-mail: [lpalmer1@arcgreatrivers.com](mailto:lpalmer1@arcgreatrivers.com)

Edna Knudsen  
Secretary & Membership Coordinator

### **Direct Dial Numbers for Staff at Blaine**

#### **Dial 763-783-ext.#**

Diane Peters ..... 4764  
Fundraising & Special Events Dir.

Jan Grieser ..... 4766  
Director of Child Advocacy

Celeste denDaas ..... 4767  
Director of Family Services

Andrea Zuber ..... 4765  
Adult Advocate

Susan Kane ..... 4769  
Family Support Specialist

Brandey Reas ..... 4958  
Administrative Assistant

**e-mail addresses are first name initial  
and last name@arcgreatrivers.com  
example: [mreich@arcgreatrivers.com](mailto:mreich@arcgreatrivers.com)**

## **Autism Services: What Do Families Need?**

*An Arc Family Forum Hosted by The Arc of Minnesota, Arc Hennepin-Carver, Arc Great Rivers, Arc Midstate, Arc Southeastern Minnesota*

**Saturday, October 30 • 12:30-3:00pm**

**Christ Presbyterian Church • 6901 Normandale Blvd. • Edina, MN**

Arc chapters statewide are teaming up for a special Family Forum to discuss services and supports for families touched by autism, and we urge you to add your voice to this important discussion. Participants will form small groups to discuss service problems and solutions regarding education, in-home and out-of-home services, recreation and leisure, medical and psychological services, and finding qualified providers. The breakout groups will then reconvene to report the key points of their discussions. Arc will record comments on major trends and issues, and the participating chapters will use the information to explore ways to address the most pressing needs. Please join us—your input is important!

This event is FREE. Space is limited—register TODAY by calling Arc Hennepin-Carver at (952) 920-0855 or register on-line at [www.archennepincarver.org](http://www.archennepincarver.org).

*Driving directions: Take Highway 100 to the West 70th Street exit and go east for one-half block on West 70th Street. The church is on the northeast corner of Normandale Boulevard (the Highway 100 frontage road) and West 70th Street.*

## **112th Annual Training Conference & Expo**

**"Conquering Change—Together We Achieve More"**

**March 15-18, 2005 • [www.mssaconference.org](http://www.mssaconference.org)**

MSSA is currently in the planning stages of its 112th Annual Training Conference & Expo. This conference is the largest, most comprehensive human service conference in the state of Minnesota. We would be very interested in having a presentation on "With An Eye To The Past." The Conference will be held March 15-18 at the Sheraton Hotel in Bloomington. Our call for presentation is available online at [www.mssaconference.org/call.pdf](http://www.mssaconference.org/call.pdf). If you are, or know of someone who would be interested in presenting, please complete and return to the MSSA office.

Director of Program Development & Communications

Minnesota Social Service Association (MSSA)

125 Charles Avenue, St. Paul, MN 55103

651/644-0556 • Fax: 651/224-6540 • [www.mnsocialserviceassoc.org](http://www.mnsocialserviceassoc.org)

## **Survey for People with DD using Technology**

The Beach Center at the University of Kansas and The Arc of the United States are working on a grant funded by U.S. Department of Education's National Institute on Development and Rehabilitation Research (NIDRR). The purpose of the grant is to learn more about how people with developmental and intellectual disabilities use technology. Although we have an online survey for self-advocates to complete on the web at <http://survey.ablelinktech.com/Quest-Net/bcstart.asp>, we also want to gather the opinions of parents and family members. Soon, a sample of people who are on the mailing list of The Arc will receive a survey for parents and family members to complete. If you receive a mailed survey, please complete and return it in the envelope provided. Thank you for your support for this important project.

*Sharon Davis, The Arc of the United States and Susan Palmer, Beach Center, KU*