Advocacy AUGUST 2019



# Celebrating the Past, Building a Future

By Delaine Petersen, Board President

This year, The Arc of Iowa celebrates 66 years of advocacy, leadership and support. As a family, Pete and I are absolutely grateful to the first pioneers in this movement who exhibited remarkable courage. Those individuals and families did not let anything stop them.

Within 3 generations, much has been accomplished. Our family is an example of just what The Arc has achieved. Never in our wildest dreams did we believe we would be parents to two (2) children with significant needs; it happened. Because of the hard work of the pioneers, our daughter Leslie and her brother, Matt (now deceased), were lucky. Neither of our children would have been able to live in the community let alone in a loving home. In fact when they were born we were advised to find "a place" for them. Thank God, we found The Arc.

Sixty years ago, there were few options for families who had a child with a disability. Parents were told that little help was available and an institution was an appropriate placement. Thankfully those parents refused to accept this minimal custodial care. Together they started local groups, met with legislators and worked tirelessly to gain the recognition that was needed. In 1953 The Arc of Iowa was established by a group of parents who came together to begin a critical organization to promote advocacy for people who had no voice.



Throughout the 1970's The Arc pushed for group homes, community based options and civil rights. As a result, state institutions once housing nearly 10,000 individuals shrunk to around 500 today with many options created. When our children were born, a new law in 1974 passed allowing for children with disabilities a free and public education.

The 1980s signaled a surge in the most important advocacy movement in the country - self-advocacy. The time had come for families and professionals to turn over some

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# The Harkin Institute - The Past That Builds Our Future

by Doug Cunningham, Director - The Arc of Iowa

The Harkin Institute for Public Policy & Citizen Engagement has announced plans for an \$8 million expansion at Drake University.

The nonpartisan organization will move into a new two-story, 16,000-square-foot building across from Drake University. It will be funded through private donations of which \$6.6 million has been raised.

The institute was established in 2013 to conduct public policy research and analysis of issues important to retired U.S. Senator Tom Harkin, including labor and employment, people with disabilities, retirement security and nutrition. It also focuses on education and outreach surrounding these issues among students and the public.

Michael Wood and Doug Cunningham of The Arc of lowa met with officials of the Harkin Institute and The Drake University History Department to discuss the opportunity of collecting historical artifacts from The Arc around the State of Iowa. They are interested in using these artifacts, information, videos, and live interviews to spearhead a history archive located at Drake University and the Harkin Institute.

Building a permanent archive with the Harkin Institute and Drake University will provide research material that explains the past struggle of those caring for and living with intellectual and developmental disabilities prior to the development of The Americans with Disabilities Act (ADA).

The group could see many opportunities for collaboration associated with sharing that information with students, future advocates and the general public.

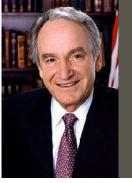
Mike reported the outcomes of this meeting with The Arc of Iowa Board of Directors on May 29<sup>th</sup> and the Board agreed to form a new History Committee of the Arc of Iowa.

The History Committee has been tasked with collecting and cateloging information from local chapters. Each chapter across lowa has its own story to share and contributions that are unique which framed the future for those with disabilities in lowa.

It is hoped that one day, this collection of data will be a library of virtual artifacts, educational curricula, and museum exhibits designed to foster research and study about the experiences of people with disabilities living in their communities across lowa.

As the information becomes available, we are reminded of how different the world was in the early 1950's, 60's and 70's. We will be sharing these stories with you in their original context. It is important to remember the past that we came from so that we can continue to advocate for a better future for individuals with intellectual and developmental disabilities.

If you would like to participate in the History Committee please contact Michael Wood at <a href="michaelwood319@aol.com">michaelwood319@aol.com</a>. If you have information regarding an Arc Chapter, even if that chapter no longer exists, we want to hear from you.



"I strongly believe that it is important to level the playing field and give eligible individuals equal access to community-based services and supports. This vital legislation will open the door to full participation by people with disabilities in our neighborhoods, workplaces, our economy, and our American Dream."

- U.S. Senator Tom Harkin on the Americans with Disabilities Act

# Flashback - New Handicapped Children's Service Begins Operations

### Tuesday, September 3, 1963

Today marks the opening of a new service for severely handicapped children in Scott County.

Under the directorship of several community organizations, a day care program began at Newcomb Presbyterian Church, 2619 N. Division St., Davenport.

Eight children ineligible for existing community projects for the handicapped are enrolled now. However, project officials said 16 children will be the máximum they could instruct.

**Directors** - Mrs. Glorene Winter, 1530 Clay St., Davenport, a former special education teacher in the Davenport system, will direct the center assisted by Miss Jeralee Matthews of 1524 College Ave., Davenport.

Miss Matthews is an experienced profesional public health nurse and a former teacher. The center actually began taking shape in January when the Scott County Assn. For Retarded Children, the Cerebral Palsy organization and the Scott County Community Welfare Council discussed possibilities of a co-operative day care center.

Since then, a federal grant of \$13,870 for the pilot project has been received, committees have been formed and many persons in the groups are working directly with the center.

Mrs. Winter said the center will begin operations this week with "individual orientation" of the children.

The program will continue nine months with two daily sessions of eight children each. Those attending must be between the ages of 5 and 16.

**Volunteer Staff** - In addition to Mrs. Winter and Miss Mathews, the staff includes a corps of volunteer workers serving as aides.

"We are hoping, eventually, to provide one volunteer per child." Mrs. Winter said.

She said children accepted for the center on a trial basis have widely divergent and multiple hándicaps - both physical and mental.

Some are non-ambulatory, speechless, have partial sight

or hearing, are epileptic, crippled, mentally retarded, or have cerebral palsy.

A specialized, coordinated child - parent program will stress efficient self-functioning and socialization on a habit - formation basis, Mrs. Winter said, and will help the child develop to full capacity.

The center will also afford some measure of relief to mothers frequently bearing a tremendous burden and may contribute to better mental health of families by giving parents the opportunity to reevaluate the impact of the handicapped child in the family.

**Assistance** - She said many parents, with assistance from programs, are not only able to keep their handicapped children in the community, but prefer to keep them at home.

Persons or agencies interested in serving on a voluntary basis for a two-and-a-half hour session, daily, weekly or monthly - or those who wish to contribute special services or equipment, are asked to contact Mrs. Winter at 324-7512 after 3:30 pm Monday through Friday, or at anytime on Saturdays and Sundays.



Newspaper Article written by Jan Strum, Tuesday, September 3, 1963.

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# Continued - Celebrating the Past, Building the Future.

by Delaine Petersen, Board President

of the control to the people whose voice needed to be heard. The 1980's were also a decade when our good friend Julie Beckett and her husband were part of a movement to create Medicaid waivers - helping support individuals to be fully included in the community. These waivers are now a critical piece of support for any person with I/DD. What would life be like without the waivers?

With the signing of the Americans with Disabilities Act, new rights were founded. During the 1990's waivers continued to evolve and serve individuals. Individuals with disabilities became more involved and learned to tell their story. And each year more self advocates become more "in charge" of their own lives.

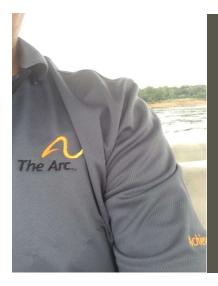
In this new century, The Arc continues to **advocate**, provide **resources** and to **communicate** the hopes and dreams of individuals.

The Arc of Iowa is proud of what we have accomplished in 66 years. We are dedicated to ensure that history is saved and that we continue to move forward. The Arc is working with chapters to save these stories. We know there are many great stories to be rediscovered.

We want to thank all of the families that have helped make these dreams a reality by remembering and recognizing their contribution. There is still much work to be done. The Arc of Iowa will continue to work hard for individuals with I/DD and their families to provide them a choice and an opportunity to realize their goals of where they live, learn, work and play.

When Pete and I reflect on the supports we have to keep our daughter Leslie in the community, it is obvious that advocacy can never stop. Today, many services are being "trimmed", denials are occurring and wait lists persist. We can't go back!

We must tell our stories - for they are important to safeguard what those before us gained. Please join with The Arc of Iowa to make sure that people with I/DD can be valued and supported citizens - 90,000 Iowans are counting on us!



# THOUGHT FOR THE DAY

"I was at a recent meeting that Julie Beckett attended. The topic was advocacy. Many of us in the group talked - what party needs to be "pushed" to get some successful outcomes for our "kids"?

Julie quietly stated - "This is not Repbulican, this is not Democrat...our kids are neither of these. They need EVERYONE."

She is right. We need to let everyone know of our family needs. And soon our public servants may become educated and informed which will result in good policy. It will take ALL of us to share our voice!

- Delaine Petersen at the FFLO Meeting

# SAVE THE DATE - MAY 2, 2020

This is your invitation to be in Des Moines for the annual **Together We Can Conference** the first Saturday in May!

The 2019 Together We Can Conference was a great success! Evaluations, reviews, and comments have been collected and, self-advocates and their families reported that they not only learned a lot but had fun!

The keynote, LeDerick Horne, a spoken-word poet with disabilities and a tireless advocate for all people, shared tools to discover our own gifts with the challenge "dare to dream." LeDerick's personal story, his practical tips, and poetry left us all inspired to reach beyond our own fears and self-imposed limits.

John Paul Derryberry from Iowa City shared his own life experience as a professional storyteller. All of us have the gift of our personal stories and John taught us how to take our own experiences and turn them into an effective story to influence the change we want to see. The other workshop topics included using mindfulness in school and at home, building skills to be a strong communicator even when the conversation is difficult, special education, and a national perspective/interactive discussion of Iowa's private Medicaid managed care (MCOs) and what is next on the horizon. The consensus of the participants is this is a really good conference with opportunities to learn new information and build your personal skills.

There is something for everyone whether you are a self-advocate, family member, or a professional working in the disability community. Check future Arc newsletters or ASK Resource website for more details as the date gets closer.



# Leading the Way!

2019 Iowans with Disabilities in Action Make Your Mark! Conference

September 26-27, 2019 Coralville Marriott Hotel & Conference Center 300 East 9th Street Coralville, Iowa 52241

This conference will help self-advocates who want to be more involved get started and those who are already active to continue to develop their skills.

Sign up today at:

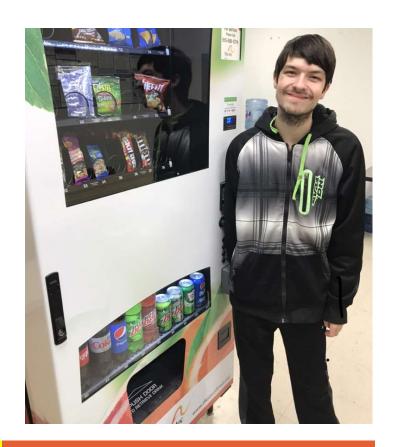
www.idaction.org

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"Getting the key to the first vending machine, I thought this would solve The Arc of Iowa's financial challenges."

- Doug Cunningham





# **Directors Corner**

When I became the director of The Arc of Iowa, it was clear that we needed to take

extreme action and do it fast. The Arc had few resources in the bank, local chapters were closing and many had lost faith in the state chapter. There had not been a director for a few years and it appeared I was to be the director that closed the doors rather than pushing barriers of this once important organization.

Thanks to a passionate and creative board, we agreed that we had to boldly grow new resources. Arc embarked on building our first vending machine - our second, our third. We then found a partner in Goodwill of the Heartland that would prove to be a like-minded organization and saw mutual value in vending machines on the floors of their stores - four and five mission based machines employing individuals with workABILITIES - ten, eleven and twelve.

Off the assembly line they would come and onto the floors of Goodwill Stores they'd go. The Arc of ECI and SEI - fifteen, sixteen. Systems Unlimited - twenty, twenty one-two-and three and finally, Goodwill lowa City - twenty eight machines in all. In 3 years, we learned, we struggled and we grew. The local chapters watched

cautiously as the state office and the board took this huge risk to ensure that the mission would not die and that lowans had a voice. We thank you for your patience.

Getting the keys to those machines was a great first step. They give us hope for a better day, stabilize our budget, provide work opportunities and afford us the ability to realize our mission.

Thanks to a strong believer in The Arc mission, we received a generous donation of \$70,000 with a challenge to match dollar for dollar the initial gift. I am asking you to help us with the **Hear My Voice Match Campaign**. Every dollar you give helps us reach that goal. These funds will pay off all of the machines, restore the strong presence and professional support to the local chapters and provide advocacy for over 90,000 lowans. With your matched gift we will once again be the voice of advocacy in this state for those with Intellectual and Developmental Disabilities.

Thank you for your continuous support and realizing that every dollar counts. Help us be a leader and support the Hear My Voice Match Campaign.

Advocate, build Resources & Communicate with selfadvocates, our members and affiliates

### Resources

## MEMBERSHIP FORM

Name |

Address |

Phone |

Email |

My Local Arc Chapter |

Type of membership (circle one)
\$ 5 Self Advocate
\$ 50 Individual & child
\$ 75 Household & children
\$125 Organization
\$500 Arc Angel

Donate to the Hear My Voice Match Campaign \$10 \$50 \$100 \$500 Other

# Make check payable to |

## The Arc of Iowa

114 S. 11<sup>th</sup> Street, West Des Moines, IA 50265



# BECOME A MEMBER TODAY BY GOING TO thearcofiowa.org

# TIME FOR THE ANNUAL MEETING

AUGUST 14, 2019 - AMES PUBLIC LIBRARY

go to www.thearcofiowa.com/board to learn more

## **AGENDA**

### AFFILIATION FEE COMMITTEE.

The Arc of Iowa Board is partnering with local chapters to re-evaluate its annual Affiliation Fee structure and to assure that the efforts of the state chapter reflect the desires of the local community chapters. This has not been done since the late 1990's and many things have changed over the years.

### HISTORY COMMITTEE

Learn about developments regarding the History Committee, updates on information collected and how the process is moving forward. For us to continue growing our advocacy efforts, we must have a solid process for remembering our past advocacy efforts and recognizing the gifts that those who have gone before us gave to us in the way of improved rights for those with disabilities.

#### **COMMUNICATION COMMITTEE**

The Arc has worked over the past year to improve

communication with its members and local chapters. This is a critical role in advocating for the needs of those with intellectual and developmental disabilities. We understand that grassroots advocacy is the strongest way to make big changes and your voice needs to be heard.

We have created a system that will allow our members to learn about what is going on and learn how to make a difference in your community.

The biggest development is the new website which will go live at the Annual Meeting. This new site has many new features and tools designed to help members get up to date information about advocacy efforts, trainings, and community events; local, state-wide and national. It is also designed to help local chapters expand their memberships, raise funds, post service opportunities, enlist the support of volunteers and be a statewide site to share what they are doing locally.

# RESOURCE DEVELOPMENT COMMITTEE

A group of chapters have come together to help build a group resource development committee. We have implemented a joint donor data base, a volunteer match recruitment tool, plan to implement a statewide Arc March Fundraiser in 2020 and will be coordinating and expanding membership drives locally.

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### **Board of Directors**

- Delaine Petersen
- Susan Teas
- Sam Houston
- Donna Bachman
- Al Fagerlund
- Alice Phillips
- Anne Armknecht
- Chelsey Holmes
- Kristen Aller
- Michael Wood
- Lonnie Polok
- Paula Connolly
- Tricia Crain

### Staff

- Doug Cunningham

If you would like to join the board please call 515-664-2252

# **THANK YOU!**

The board of directors would like to thank the chapters that have opened their doors to Michael Wood and Doug Cunningham to learn what is happening in your chapter and to work with The Arc of lowa to advocate, secure resources and communicate with one another.

Learn more about what is happening across the State by going to:

www.thearcofiowa.org



Watch for our November Newsletter which will include: A candid interview with Total Care- the new MCO, the 2020 US Census and how your participation affects the money your community receives, updates on committee efforts & annual financials.

# Achieve with us.

Become an individual member of The Arc of Iowa and help friends and neighbors in your community.

Go to www.thearcofiowa.org and click on Become A Member.



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