



For people with intellectual
and developmental disabilities

Early Summer 2020

CONNECTION

Published quarterly by The Arc Tennessee

Achieve with us.

A Pandemic Victory Tennessee Improves State Guidelines Prohibiting Discrimination in Healthcare Rationing

By: Dara Bacon

The COVID-19 global pandemic has brought about many challenges and drastic changes for all people, especially people with disabilities. In these last four months, now more than ever, The Arc Tennessee has worked to provide information, connect people to resources and advocate for the equal rights of individuals with intellectual and developmental disabilities.

On Friday, March 27, 2020, The Arc Tennessee (The Arc TN) collaborated with several individuals with disabilities, their families, Disability Rights Tennessee and other disability advocacy organizations to file a complaint with the Office of Civil Rights (OCR) about "Tennessee's Guidance for the Ethical Use of Scarce Resources during a Health Emergency."

The complaint voiced grave concerns that the plan discriminated against people with disabilities in violation of federal disability rights laws, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504) and Section 1557 of the Affordable Care Act (ACA), placing lives at risk. Complaints called on OCR to take immediate action to address this discrimination and assist local jurisdictions and providers to develop non-discriminatory policies before there were lethal consequences for honoring these illegal policies.

We knew the message these policies conveyed did not reflect the worth and dignity of people with disabilities. So, we worked with our partners to advocate for the Tennessee rules be changed.

Since the complaint was filed, we have worked with our partners to review plans from other states and Tennessee's proposed plan. We are happy to report that the complaint has been addressed, and that Tennessee's revised "Guidance for the Ethical Allocation of Scarce Resources During a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee" does not discriminate against people with disabilities. Our hope that in sharing these updates, is that all individuals will better know their state

and federal rights throughout this pandemic. Here is a quick list of key revisions to the guidelines:

- Removal of categorical exclusions based on disability in favor of individual assessments. An individual can no longer be excluded from treatment based solely on a diagnosed disability.
- Narrowing the scope of survivability assessments from one year to imminent survival.
- Requiring reasonable modifications when necessary due to disability. This includes modifications to survivability assessment tools. For example, a person's speech disability may negatively impact these assessments even though they do not have a lower likelihood of imminent survival.



Greg Ridley, an individual supported by The Arc Knox County, reminds us that we are in this together!

To review the complete guideline updates and other important information like hospital companion guidelines, visit theartcn.org/COVID19.

It is encouraging that Tennessee's plan is now seen as the national standard for allocating scarce healthcare resources if it should become necessary during this pandemic or any healthcare crisis. We are grateful for a victory and hope this information provides comfort and encouragement as we all endure this challenging time.

**Si tiene un niño o miembro de la familia con una incapacidad intelectual o de desarrollo, puede contactar
Pathfinder a: 615-875-5083 para recibir más información sobre recursos y servicios.**

FY 2019- 2020

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The Arc Connection is funded
under an agreement with
the State of Tennessee and is
published quarterly. Articles
should be sent to:

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Deadlines for issues:

Summer	9/1/20
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CALENDAR REMINDERS

<u>Date & Time</u>	<u>Event</u>	<u>Place</u>
July 21st, 10am & 5pm	People First Social Hour	Zoom invite, members only
July 24th at 7pm	Virtual Bingo Party	Register on thearctn.org
July 25th, 3pm	Virtual Bingo Party	Register on thearctn.org
July 28th, 10am	Virtual Bingo Party	Register on thearctn.org
Aug. 4th, 10am & 5pm	People First State Call	Zoom invite, members only
Aug. 18, 10am & 5pm	People First Social Hour	Zoom invite, members only
Oct. 28th at 3pm (All events CST)	The Arc TN Awards Banquet	Zoom, register online beginning in August

<http://www.thearctn.org/Calendar.php>

MISSION STATEMENT

The Arc Tennessee empowers people with intellectual and developmental disabilities
and their families to actively participate in the community throughout their lifetime.

<http://www.thearctn.org>

We Will Miss You Carrie!

Carrie Guiden Leaves The Arc Tennessee

In April our beloved Executive Director, Carrie Hobbs Guiden, moved on to another organization. We are taking this opportunity to reflect on the last ten years of her time with us and what it meant to individuals with intellectual and developmental disabilities (I/DD), families, our board of directors, our team and others across the state and those across the country whose lives she has touched within The Arc family. Carrie is a collaborator. Partnering with other organizations made so much more possible. Here are some of The Arc Tennessee's accomplishment's under Carrie's leadership:



Impacted Important Legislation:

- Tennessee Positive Behavior Supports Act
- Aging Caregiver Legislation
- Supported Decision-Making Legislation
- Affordable Care Act and then blocked its repeal
- Continuing to be part of the advocacy work to keep Medicaid from becoming a block grant



Represented Individuals and Families as:

- Chair of DIDD's Disabilities Developmental Planning and Policy Council
- Being part of the development of the Employment and Community First (ECF) CHOICES program
- Work on Supported Decision-Making in Tennessee
- Relaunching of People First Tennessee



The Arc TN Growth & Recognition:

- Secured funding/support for the Tennessee Center for Decision-Making Support
- Secured a Healing Trust Advocacy Grant
- Tennessee Disability MegaConference
- Roll-out of Office Daily
- Funding then Expansion of the Family Engagement Project
- The Arc Tennessee hosted The Arc National Convention in 2018
- Growth of Light up a Life
- The Arc Tennessee received a Center for Nonprofit

Throughout the years, Carrie supported many self-advocates in leadership roles within The Arc Tennessee. She received the Amerigroup Healthy Heroes Award and the NCE Executive Excellence Award. These are just a few highlights of Carrie's time with us. She notes that by having had the opportunities to attend the Disability Policy Seminars, The Arc National Conventions and NCE Summer Leadership Institutes, she had the opportunity to more deeply experience the impact The Arc has on the lives of people with I/DD and their families. We will truly miss Carrie at The Arc Tennessee. We wish her all the best!



Lines from Linda

By: Linda Brown, President

As I write this article, I am thinking of all the transitions that have taken place since the beginning of

2020. We began the year with the great success of Disability Day on the Hill and watched the many self-advocates speak to their representatives about the issues that are important to them. I have to say a huge thank you to Dave Griffin, Coordinator for People First and all the effort he put into getting appointments scheduled for the People First members. Another transition for The Arc Tennessee was the departure of our Executive Director, Carrie Hobbs Guiden. Carrie was with The Arc Tennessee for 11 years and did a remarkable job. Her passion for the disability community was demonstrated in the number of hours she devoted to the staff and community. We are fortunate that she will still be local and still involved with the disability world. We wish her all the success in her new endeavors.

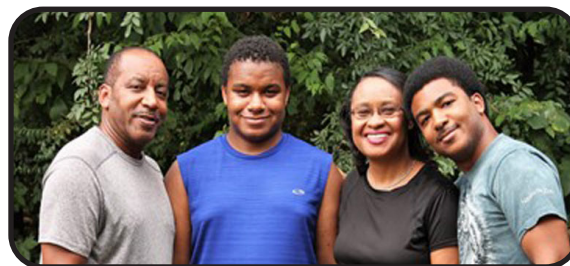
Our community also experienced the March 3rd tornadoes. Through my work at Tennessee Disability Pathfinder, I was able to speak to individuals affected by the tornadoes and to people in the community that were willing to help individuals that was affected by the tornadoes. Although it was a stressful time, it was great to see how the community pulled together to help their neighbors.

Of course, next was COVID-19. This has been the biggest transition of all. Our nation has been forced to make major changes in daily living. Work from home, wearing protective masks, closure of many retail stores, barbershops, etc. For some, it has been a positive experience in that we have become more connected as a family, learned new technology and/or became more active with exercising on the walking trails. For our family, I believe it has been positive.

Of course, there have been times that we were bored and had to think of different things to do. Fortunately, our family likes to ride around and see different neighborhoods and go to Dairy Queen for ice cream. I am fortunate that I have been able to work from home. My family has been very respectful in the noise level when I am on the phone or one of many Zoom calls. I must admit that I am not missing the Nashville traffic.

As we go through this transition, it gives better insight into what our loved ones with an intellectual or developmental disability go through daily. I say this in the respect of having to be isolated daily. I gained a better understanding of wanting to go somewhere but couldn't. I was thinking, I wonder if this is how our son felt, or others in his situation, felt; wanting to go somewhere but couldn't because of various reasons (working parents, transportation). I have other people talk about how they are lonely, bored or how we are supposed to be in a community. This is not always the case for our loved ones.

Yes, as a family we provide them with support, love and attention; but there comes a time when they will want to build a community of their own and gain new friends. When we do return to our lives before COVID-19, I hope people will continue to reach out to the disability community. Continue to find ways to help them be included in a productive and happy life. Let's all pray that the spirit of love and giving continues so that everyone know that they are important in this world.



Jeff, Terrell, Linda & Myles Brown



On Thursday, May 21st, over 500 people participated in the first virtual Tennessee Disability Megaconference! Even COVID-19 couldn't stop the Megaconference team from delivering informative sessions on Pre-Employment Transition Services, building a successful DSP team, dementia, enabling technology, financial tools to preserve public benefits, successful self-advocacy and much more!

With support from Amerigroup, Disability Rights Tennessee and Easter Seals, we were able to offer free Registration to all participants! Mark your calendars for May 20th and 21st for the Tennessee Disability Megaconference at the Nashville Marriot Hotel.

For more information, visit www.tndisabilitymegaconference.org.





FESPED-TN
FAMILY ENGAGEMENT IN SPECIAL EDUCATION

Family Engagement Project Updates!

By: Jennifer Aprea, Family Engagement Coordinator

Exciting things have been happening in the world of Family Engagement in Special Education even during a global pandemic! We are excited to share that our grant expansion from the Tennessee Department of Education came through, and we will be growing our team by nine amazing new people! We have hired a Communications Specialist to oversee our digital marketing, social media, and email newsletters. They will also lead up the new Family Engagement Resource website that will be coming soon to help families across the state find fast and easy resources about special education in Tennessee.

Since Governor Lee recommended schools close for the remainder of this school year in April, we have been working closely with the Tennessee Department of Education to keep families informed on what this means for their children who receive special education services. We have a regularly updated resource for families on our blog at:

<https://bit.ly/CovidFamilyResources>

We were honored to work with several other grant-funded programs through the Department of Education to create a comprehensive resource for families looking for supports to help their children through this time of staying home. If you would like to see if there are any resources that would help you or someone you know, please visit

<https://bit.ly/TNspedfamilies>

There are resources from The Arc Tennessee, Project PAVE (providing access to the visual environment), Project Therapeutic Recreation in Public Schools (TRiPS), Tennessee Behavior Support Project (TBSP), Tennessee Talks Project, TransitionTN, and Treatment and Research Institute for Autism Spectrum Disorder (TRIAD).

Finally, since the last week of April we have been holding Facebook Live Question and Answer Sessions specifically related to questions families have about special education in the time of school closures. We have been fortunate to have Lauren Percy from the Council on Developmental Disabilities, Commissioner Penny Schwinn from the Department of Education, and Assistant Commissioner of Special Populations Theresa Nicholls join Jennifer Aprea via Zoom to answer questions and discuss issues and updates related to Special Education in our Tennessee schools. This series will continue weekly for the coming weeks as the state continues to put out guidance for schools so we can update families in real time. Please join us on Wednesdays on The Arc Tennessee's Facebook page at www.facebook.com/TheArcTennessee

I Miss My Friend Shirley

By: Penny Kong, Mother & Advocate

Contributing Writer: Christopher Covington



Steve Jacobs, Penny Kong and Shirley Covington

My friend Shirley Covington was born 4/5/1943 and passed on 3/3/2020. She was 76 at the time of her death.

Shirley was married for more than 20 years to Robert Frederick Covington, who died in 1991. Fred was her high school sweetheart and Shirley never missed the opportunity to speak of how much she still missed him and loved him.

Shirley had three children: Julia, Christopher, and Craig. She had five grandchildren and two great grandchildren, whom she bragged about endlessly! I loved to hear her stories of her love for her family and also how much Fred loved Craig and his brother and sister. It was easy to see that Shirley loved people. She also loved to garden.

I was able to get to know Shirley over the past five or six years, through her visits with her youngest son Craig, who happened to be a person with an ID/DD. She tried to never miss her weekly visits with Craig every Thursday and enjoyed bringing him gifts of all kinds including clothing, ice cream and toy robots.

She never stopped seeking the best quality of life for Craig, and through her tireless efforts, she often sought out the "good fight" to improve our system of supports for him.

Over the last year of her life, she was blessed with both a new provider of supports for Craig, and also cherished the care provided by the Direct Support Professional that worked with him.

Shirley often showed her love and support of Penny, and always managed to thank her for the love and care she provided to Craig. I know Shirley truly missed Penny when she relocated out of state, and I'm equally sure that Craig misses both Penny and his Mom.

We never got the chance to say good bye but I'm certain we will meet again in a better place.



Loria's Loft

*By: Loria Hubbard
Interim Executive Director*

This has been a surprising spring. Individuals with intellectual and developmental disabilities (I/DD), families and their children, and our team at The Arc Tennessee have all found ourselves sequestered at home in an effort to be safe from the threat of COVID-19. Schedules have been turned upside down, making life confusing. The situation has been difficult to understand for the folks we serve. We have been concerned with catching the virus or with possibly spreading it to others. Schools have been closed. Families have had to learn to quickly become educators and to learn new policies. We have all had to learn how to avoid the coronavirus:

There have been new policies and laws passed that have been helpful during this time. It is important to be familiar with them.

The CARES Act has passed Congress. This has included:

- Stimulus payments (thanks to your advocacy efforts individuals with I/DD were not required to file tax returns for 2019 in order to receive these payments)
- Small Business Administration Payroll Protection Loans to help organizations cover payroll during COVID-19 to prevent lay-offs
- Increased funding for education
- Federally subsidized unemployment benefits

The Secretary of Education was required to report to Congress on the need to waive portions of the IDEA (Individuals with Disabilities Education Act) and Section 504 of the Rehabilitation Act. An important win for our community was when Secretary DeVos reported after 30 days that there was no need to waive any portion of these important civil rights for students who receive special education services and have accommodation needs. As of this writing Package Four of this Bill has passed the House but we are still waiting for action from the senate. It includes:

- Dedicated funding for Medicaid home and community-based services (HCBS)
- Personal protective equipment (PPE) for direct support professionals
- Paid leave for all caregivers
- Economic impact payments for all people with disabilities

The Department of Intellectual and Developmental Disabilities submitted Appendix K to Home and Centers for Medicare & Medicaid Services - CMS and it was passed. This provided for:

- Flexibility in service provision to allow for persons to remain at home
- Options for staffing ratio flexibility, enabling technology

utilization, and telehealth services

- Temporarily modify regulatory requirements and other waiver provisions
- Bolster provider and staff stability through temporary rate adjustments and hazard pay for DSPs

The Arc Tennessee's Family Engagement project has partnered with the Tennessee Department of Education's Division of Special Populations to bring Facebook Live events each Wednesday on The Arc Tennessee's Facebook page, throughout the COVID-19 crisis. Topics include the Department's response, policies, guidance, and families' questions are answered. The State has provided for flexibility for the 2019-20 school year as a result of the public health emergency by allowing for flexibility in evaluation timelines. They have given schools flexibility, but they have not given them the right not to educate children with disabilities. They have provided lots of resources on the State Department of Education's COVID-19 Resource page for schools and families.

There are many changes and challenges right now, but we are all in this together. It is important for all of us to find ways to stay in touch with one another. The Team at The Arc Tennessee has begun having Friday Check-ins to build on our cohesiveness. We love that Lamont wears a different bow tie each Friday, that Steve is always on the back porch, and that Therese laughs at everything. We brainstorm together for solutions. We share successes. We are all in this together and we're still here for you as we have always been.

The Department of Intellectual and Developmental Disabilities (DIDD) just released that they will be partnering with the Division of TennCare to integrate and align all Medicaid long-term services and supports (LTSS) programs for people with intellectual and developmental disabilities (I/DD), including the Section 1915c HCBS waivers, the Employment and Community First CHOICES Program, and Intermediate Care Facility Services for Individuals with Intellectual Disabilities (ICF/IID), for the first time, under the direct operational leadership, management and oversight of DIDD. This is planned for implementation by July 1, 2021.

A PODCAST FOR SELF-ADVOCATES & FAMILIES

Nashville's New Horizons Life Skills, a non-profit organization that supports adults with intellectual and developmental disabilities, has launched the Trailblazer Podcast. This podcast was created as a platform for the disability community to directly share stories and perspectives, stirring conversations and prompting action. Check out all the Trailblazer podcasts on New Horizon's website <https://newhorizonsls.org/podcast> or on Spotify! **If you're interested in sharing your story or want to nominate someone to be a guest, please email podcasts@newhorizonsls.org.**



*By: Dave Griffin,
People First Project Coordinator*

Coronavirus is not stopping People First! We had three lively, enthusiastic, and upbeat State-Wide Conference calls in March, May and June. The next conference call is planned for 10 a.m. on Tuesday, August 4, 2020. Anyone, disability or not, is welcome, but you must first be a People First member to participate. Memberships are available on The Arc Tennessee website www.thearctn.org.

In case you missed our meetings, we discussed these topics in March: Covid-19, the 2020 Census, Covid-19, Membership, and the Membership Drive. Through emails that People First members receive, The Arc Tennessee has been updating members on policies associated with COVID-19 and resources available to help cope during this difficult time. Lauren Percy, Public Policy Director for Council on Developmental Disabilities, helped explain some of the finer points of COVID-19. Please complete the 2020 census, because it helps ensure Tennessee gets all the services we need for people with disabilities. We had three People First Advisory Council members on the phone: Mary Dale Greene, Diamond Grigsby, Marcelous Brazley, and Garrett Jones. We also had many officers from chapters throughout the state on the call: Lorri Mabry, Davidson County President; Pisanach P. Chinratanalab, Davidson County Vice President; John Harris, Rutherford County President; and Terrell Brown, Rutherford County Secretary. We had well over 20 members on this call.

In May, like in April, we offered information and assistance in receiving stimulus checks. Andrew Austin from New Horizons was on hand to invite People First members to produce podcasts about topics of interest. One of those was done by yours truly, highlighting the events in my life that led to my current position with The Arc Tennessee. You can also hear Pisanach P. Chinratanalab describe her own journey in a separate podcast. Joey Williams, Davidson County Chapter Sergeant of Arms was on the call, as well as Josh Riley, Davidson County Secretary from the same chapter. We also had William County Vice President Tom Curl, on the call with us. We had at least 26 members

join us for this meeting. We really enjoyed being able to see each other through zoom technology.

On Tuesday, May 26, 2020, we launched a "People First Social Hour," thanks to supporter Heather Henderson with DIDD. This is Zoom call for self-advocates and their supports to just talk about fun topics of interest. I am planning ice-breaker questions and hope to play some virtual games on line in the future. It's also an opportunity to just talk about anything we want since we aren't able to physically meet at this time. Find and use your voice in a relaxed atmosphere by joining our next scheduled social hours

Our next State-Wide Conference call will be on Tuesday, August 4, 2020 at 10:00 a.m. CST. Mark your calendar. We've had 84 new and renewed memberships recently. I would like to at least double that number by September 1st, 2020. If you know someone who would like to join People First Tennessee, please reach out to me at dgriffin@thearctn.org. I will be sure to get your name listed as the person who made the referral. Thanks to all who make People First such a success!



FOR YOUR GENEROUS DONATIONS!

This listing reflects donations received 1/1/20 - 6/1/20. We apologize for any omissions and appreciate omissions brought to the attention of Gavin Dillinger at gdillinger@thearctn.org or 615-248-5878 x 17.

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BE COUNTED! Take the Census.

What is the census?

The government counts everyone in the country. They ask questions about every home in the country. One person from every home answers the questions. This is called the census. **The census is when the government counts everyone in the country.**

The census happens every 10 years. **We will have a census in 2020.**

The government will send you a letter in the mail. They sent letters in March. This letter has instructions on how to fill out the census.

The census asks one person in every home to answer a few questions. A home can be a house or apartment.

What questions does the census ask?

The census asks two kinds of questions. It asks questions about your home. Then, it asks questions about each person who lives in your home.

The census also asks questions about you.

The census asks these questions about your home:



What is your phone number?



Do you own your home or rent it?



How many people live in your home?

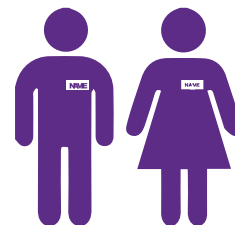
Only one person needs to respond to the census in each home. If you live with other people, you should talk to them about who will fill it out.



Your answers to the census are **secret**. The government will not share your answers with anyone. Your answers are used to count how many people there are in the country. **The law does not allow your answers to be shared for any other reason. The census does not ask if you are a citizen of the United States.**

The census will ask:

- **What is your name?** You put your name on the form.
- **What is your sex?** The census gives two options. You can choose “male” or “female.”
- **What is your age?** You put down how old you are on the form.
- **Are you Hispanic, Latino, or of Spanish Origin?** This question has to do with where your family comes from. The form uses the term Hispanic, Latino, or of Spanish origin, so if your family comes from a Spanish-speaking country, your answer to this question is probably yes.
- **What is your race?** For this question, you check boxes. The census lists different races. Some examples are “white,” “black,” or “American Indian.” You can check more than one box. After you check boxes, the census asks for more details, like what area, country, or tribe your family is from.



The census will also ask these same questions about the people who live with you.

Is it really the census?

Sometimes, people will mail you spam that says it is from the census. Here is how to tell if mail that says it's from the census is real or fake:

The census
will **not**

SSN

ask for your Social
Security number



send people to jail
for not answering
questions



ask for money or
your bank account
information

Why is the census important for people with disabilities?

The law requires the census to collect information for the government. The government uses that information to make decisions. These decisions affect people with disabilities. There are two main ways the census affects people with disabilities.

1 Money for services and programs

Information from the census is used by federal, state, and local governments to make decisions about funding for services and programs. These services and programs include education, housing, health care, transportation, and other community needs. People with disabilities can benefit from these services. All communities benefit from these services.

Everyone needs to be counted to make sure the government has the right information to make decisions about these important services. Having enough money for programs and services for people with disabilities depends on having the right information. That is one reason why it is important for all people with disabilities to be counted in the census.



2 Representatives in Congress



The federal government makes laws for the whole country. The people who make these laws are called Members of Congress. Members of Congress are the people who make laws for the whole country.

We vote for our Members of Congress in elections.

One part of Congress is the House of Representatives. The Members of Congress in the House of Representatives are called Representatives.

Every state has a different number of Representatives, based on how many people live in the state.

Remember, **the census counts how many people live in the whole country and in each state. The government uses that number to figure out how many Representatives the state should have.** If people don't fill out the census, a state might get less Representatives. Then, the people in that state won't have as much of a say about decisions in Congress.

We need to make sure every state has the right number of Representatives.

How do I fill out the census?

The government sends you a letter in the mail. They will send the letter in March 2020. This letter has instructions on how to fill out the census online.

There are three ways to fill out the census:

Remember, only one person in your home can fill out the census. If you live with other people, you should talk to them about who will fill it out.

There are guides to help people with disabilities fill out the census. There are large print guides. There are also guides in braille. If you have questions, you can call 1-800-923-8282 or go to **2020census.gov**.



ONLINE



PHONE



ON PAPER

If you do not fill out the census, a census worker may come to your home to help you fill it out. They may come in May, June, or July.

Are they a real census worker?

All census workers have a badge proving they are a census worker. You can ask to see their badge to check that they work for the census.

Every census worker's badge has four things on it:

1. The badge says "Department of Commerce."
2. The badge has the worker's name printed on it.
3. The badge has a picture of the census worker.
4. The badge has an expiration date on it. That means that the census worker can use the badge until that date. But they cannot use the badge after that date.

A real census worker has all 4 things on their badge.

For More Resources, Visit [TheArc.org/Census](https://thearc.org/census)

Winter 2020



Achieve with us.

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The Arc Tennessee, 545 Mainstream Drive, Suite 100, Nashville, TN 37228-1213

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Card number _____ Verif. Code _____ Exp. Date _____
Signature _____

____ Enroll me as a member (\$20 Individual, \$5 Self-advocate, \$100 Business Associate)

I would like my gift to be: ____ in honor of: _____ ____ in memory of: _____
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____ Send me information about including The Arc in my will.

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