



**The Arc**<sup>TM</sup>

Pennsylvania ————— Winter 2021 - Volume XXII, Issue 2

# Pennsylvania Message

## 50 YEARS AGO...



Excerpts from the PA Message, Winter Issue, 1970-71 announcing the Right to Education Suit

“One of the most monumental actions in the history of the Pennsylvania Association for Retarded Children was recorded on Jan. 7 when Attorney Thomas K. Gilhool of Philadelphia, entered the office of the federal district court clerk here, turned over a 30-page legal complaint, a \$15 check and waited for assignment of a judge.

For PARC, that simple formality was both a culmination and a beginning. Thousands of retarded children in the Commonwealth of Pennsylvania have been denied a public education, the suit charges. It asks for both preliminary and permanent relief which, if granted, would become a national landmark victory for the retarded.

What is being contested? The Pennsylvania Association for Retarded Children is charging the Commonwealth with violating the 14th Amendment to the Constitution which guarantees equal

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Excerpts from the PA Message, June 1972 Announcing the PARC Consent Decree

“On Friday, May 5, 1972, the three Judge Federal Panel signed the historic consent agreement between the Pennsylvania Association for Retarded Children and the Commonwealth of Pennsylvania, which mandates that retarded children **MUST** be afforded the free, public education originally legislated in 1955. (Judge Arlin M. Adams, Judge Raymond J. Broderick, Judge Thomas A. Masterson) Under the order, the public schools can no longer refuse to accept pupils aged 5-21 because they are mentally retarded.

In his written opinion, Judge Masterson said, “Today, with the following order, this group of citizens will have new hope in their quest for a life of dignity and self-sufficiency.”

Governor Milton J. Shapp, at a speech given Friday, May 12, 1972 which served as a kickoff to the Right to Education Implementation said “Today, we embark upon a new era in

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Throughout this newsletter, the phrase “mentally retarded” is used instead of “intellectual and developmental disability” when quoting language from the Right to Education Lawsuit. Those were the words used in the seventies when the lawsuit was written, but we know better now.



# President's Message Jessica Capitani



My son went to school today!

This should be a simple statement. Indeed, it is one that many parents can take for granted. But my son has Down syndrome and attending school has not always been a given for children with Intellectual and Developmental Disabilities (IDD). In fact, children with disabilities were considered “uneducable” until the landmark PARC Consent Decree. The PARC Consent Decree, signed fifty years ago, established the unconstitutionality of denying a free publicly funded education to children with IDD. As someone whose child has known nothing but the benefits of that historic settlement, it is inconceivable to me that prior to PARC v. Pennsylvania, children with disabilities may instead have spent their days in the back room of their homes or in an institution.

I recently watched an interview of Jim Wilson, the president of PARC (Previous

name of The Arc of PA) from 1968-71 and was struck by his admission that he did not understand the full implications of what might happen if the class action lawsuit was successful. He said many parents were dumbfounded by the news as they had never considered formal education a possibility for their children. He described The Arc of Pennsylvania as “beating the drums to get the word out to create the ripple effect.” However, this lawsuit did not create ripples of advocacy. Rather, it unleashed a tidal wave. PARC v. Pennsylvania was the first right to education lawsuit in the country but similar legal challenges in other states quickly followed. And the PARC Consent Decree became the foundation for federal legislation.

I am extremely proud of The Arc of Pennsylvania’s role in this victory so pivotal that it forced a paradigm shift. Education opens doors to employment

and independence. People with IDD are accomplishing, contributing, and living in ways that were not possible just two generations ago and education has been an invaluable contributor to their achievements.

The right to education movement has also been described as a mother’s movement since it was the mothers of children with IDD at the forefront of the call to action. As a parent, I am gratefully and humbly appreciative of those trailblazers that paved the way. Their legacy is that children with disabilities became students. This should be a simple statement but because of the significance of the history behind it, it will always be with profound reverence that I say my son went to school today.

– Jessica Capitani



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# Executive Director's Message Sherri Landis



We are celebrating the 50th year anniversary of the Right to Education lawsuit which resulted in the PARC Consent Decree and a national change for the education of ALL children with disabilities. This decision brought The Arc of PA (then known as the Pennsylvania Association for Retarded Children) into the forefront as conversations about the education of children with disabilities began to take center stage across the United States. We are so thankful to the PARC Officers and board of directors who took the dramatic step to file a class action lawsuit and to Attorney Thomas K. Gilhool who was the fantastic legal mind who guided and litigated the lawsuit on our behalf.

The legacy of The Arc was built on this lawsuit and others related to the conditions and the closing of Pennsylvania's state centers. It is this legacy that we strive to uphold in the work we continue to do each day. I want to, once again, bring your attention to The Arc of PA's new strategic plan. It outlines how we continue to live up to the values and the passion on which this organization was built. Our plan was developed with input from our board of directors, local chapters, and volunteers, and reflects the elevation of the voices

of individuals and families. You can find our strategic plan on our website at [www.thearca.org](http://www.thearca.org).

There was a time in PA and across our nation when children with disabilities could not attend their local school. Parents were told by professionals that the only opportunity for any "treatment" was at a state-run center. PARC parents wanted something different. They wanted their children to be treated like everyone else, given the same opportunities, including the opportunity to attend school. And not just any school - their neighborhood school. And that meant that the supports and services needed for a successful school experience must be provided to each student.

While we have much to celebrate over these past 50 years, we also know there is much to do. We still have a number of educational issues that need to be resolved in PA, including:

- Prioritize an inclusive educational experience for ALL students with IDD (Intellectual and Developmental Disabilities)
- Support recruitment and retention of qualified staff
- Promote better coordination and access to vocational education for students with more complex needs
- Shift the Burden of Proof to school districts in a special education due process hearing
- Apply the special education funding formula to charter schools
- Assure fair school funding and funding for special education services
- Disciplinary procedures that are fair for all students regardless of disability, race and ethnicity and that follow due process procedures

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## GO GREEN

The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to: [info@thearca.org](mailto:info@thearca.org) to receive your electronic copy.

*Achieve with us.*

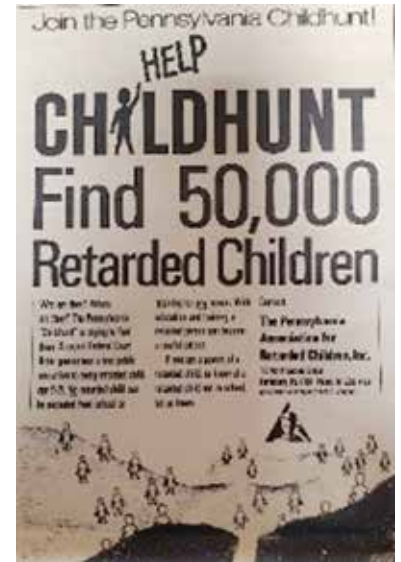
protection. It is contesting a state statute which provides that a child entering public school must be five years old mentally. And PARC points out its resistance to a state proviso that a child may be excused from classes on the basis of psychological tests.

Defendants in the class action include the Commonwealth of Pennsylvania, the PA State Board of Education, and the PA Department of Public Welfare, and a variety of local school districts.”

the educational training of mentally retarded children. In the 1870's, schools for the mentally retarded were, little more than dumping grounds for children with learning disabilities who bothered the regular class teachers and were, in many instances, merely the non-English speaking children of immigrant parents. Today we affirm the commitment of the Commonwealth of Pennsylvania to provide every mentally retarded child in the state with a meaningful program of education and training no later than September 1972.”

**G**etting an education is so important. My mother is a retired special education teacher, but years ago, she knew all my teachers. I had wonderful teachers. My favorite classes were Home Economics and Shop Class. My classes really prepared me to be more independent.

— Mr. Joshua Stranix  
*The Arc of PA, Board of Directors, Secretary*



Following the PARC Consent Decree, the first job was to find all the children.

In Touch is an electronic newsletter that is emailed every 2 weeks. It shares the most up to date information about legislative and governmental actions, resources, and events. If you'd like to receive it, email [info@thearcpa.org](mailto:info@thearcpa.org).

## LEARN MORE, DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at [pie@thearcpa.org](mailto:pie@thearcpa.org) to receive electronic alerts and the quarterly newsletter.

# INCLUDE ME PROGRAM CONTINUES FOCUS ON LRE

Nicole Turman, Program Director, Include Me/ADEPT, The Arc PA

“Never doubt that a small group of thoughtful, committed citizens can change the world: indeed, it is the only thing that ever has.” — *Margaret Mead*

## Fifty Years Ago

Fifty years ago, a small group of thoughtful, committed families set out to change the world for children with intellectual disabilities in Pennsylvania. Collaborating with Attorney Thomas K. Gilhool of the Public Interest Law Center of Philadelphia (PILCOP), The Arc of Pennsylvania (PARC at the time) secured the right to education for children with intellectual and developmental disabilities, not only in Pennsylvania, but because of their efforts, across the country.

A landmark agreement and consent decree was reached after only one day of testimony by only four of seven scheduled expert witnesses in August 1971. The agreement was affirmed on October 7, 1971. In the PARC Consent Decree, the court affirmed “access to a free public program of education and training, appropriate to one’s learning capacities, to all children with intellectual disabilities between the ages of six and twenty-one.” The decree went on to state “... placement in a regular school is preferable to placement in a special school and placement in a special school class is preferable to placement in any other type of program of education and training.” This language is our first address of ‘inclusion’ as it relates to educating students with disabilities.

## Decision Expanded by Federal District Court

Shortly after the Pennsylvania court issued the final opinion, the Federal District Court in Washington DC issued a decision that expanded the PARC v. PA Commonwealth ruling to cover all school aged children with disabilities nationwide. Congress then set out to secure that right to education for children with disabilities through legislation. Along with Congress, PARC aided in drafting the federal right to education law, what we now refer to as the Individuals with Disabilities Education

Act or IDEA. The original law was called the Education of the Handicapped Act and was signed into law in 1974.

## What is LRE and why is it important?

LRE stands for the Least Restrictive Environment. But those are just words. What do those words mean? Is LRE inclusion? In a way, but not exactly. LRE is Congress’ way of ensuring that students with disabilities have access to the array of services and supports they need to benefit from their public education. Many efforts and attempts to define LRE (and, by extension, inclusion) have been made over the years since the PARC Consent Decree and the first iteration of IDEA were affirmed and enacted. The appropriate adage to describe why inclusion is so important is - When we know more, we do more. When we know better, we do better.

Over these 50 years, there have been many hearings and court rulings that helped clarify the definition of LRE. The experts, as well as families and students themselves guided us to also consider the social benefits of students with and without disabilities learning together. And schools responded by finding opportunities to build social interaction for students. We learned more about differentiated instruction and modifying curriculum. We learned about the kinds of supports which are available to teachers and classrooms to support access to the curriculum that students without disabilities were learning in school. We adjusted our approaches and expectations to include students with disabilities in academic instruction.

We continue to learn and find ways to apply the principles of universal design to make our classrooms more accessible - not only the physical space, but the content of learning in the classroom - to all students.

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*Patricia Fornof Clapp*

*March 10, 1929 – November 26, 2021*

Join The Arc of PA in remembering Mrs. Patricia Fornof Clapp. Mrs. Clapp passed on November 26, 2021 at the age of 92. She served as President of The Arc of PA during the time of the Right to Education Lawsuit and it was said, the wording was written at her kitchen table!

### Applying our commitment to LRE

The Arc of Pennsylvania continues this effort. A group of committed, thoughtful staff work with Pennsylvania school districts through The Arc's Include Me program to expand the understanding of the least restrictive environment, to better define what it means to include - socially, academically, and in extra-curricular areas. The Arc of PA is grateful for its partnership with the PA Department of Education, Bureau of Special Education in this journey to support the inclusion of all students, with and without disabilities, in their neighborhood schools, learning, playing, working, and growing together. The Arc's Include Me program expands that early vision of the right to education for all children. Our staff support districts as they include students in the full curriculum, with full participation in the school community, and planning for a life of contribution, value, and participation in community life after school.

The Arc of PA's Include Me program specialists work with participating Pennsylvania school districts to:

- Create school cultures that embrace and empower all students
- Incorporate principles of universal design for learning
- Presume competence in all students
- Find value in each student's participation in the classroom and school community

Our work is not finished, but we are on our way. We know that teachers, administrators, community partners, and families are all critical to the foundation and practice of what we call inclusive education. Let us all be inspired to join the effort and learn more so we can do more.

*For more information about The Arc of PA's Include Me Program, contact Nicole Turman at [nturman@includemepa.org](mailto:nturman@includemepa.org).*

## ENSURING THE INTENT OF THE RIGHT TO EDUCATION CONSENT AGREEMENT BY CREATING THE STATE AND LOCAL TASK FORCE SYSTEM

The PARC Consent Decree created both the State Task Force and 29 Local Task Forces across Pennsylvania. Their purpose is to ensure that the intent and the spirit of the Right to Education Consent Agreement is carried out throughout the Commonwealth. One LTF shares its story.

### Local Task Force 20

When I was asked to provide information as the Chairperson for the Local Task Force 20, all I could think was, "How do we make a difference as parents and professionals?" The word "FORCE" came to mind. More specifically, joining forces with individuals to create effective action.

The strength, energy, and commitment from everyone that serves on the LTF can make a difference in a student's right to access his or her education. Consumers (family members) and agency representatives are passionate about carrying out the Right to Education Consent Agreement. We are committed to improving and strengthening services for school age children.

To strengthen these services, the Local Task Forces collaborate with school personnel, outsource information, and provides support to parents/families of children with disabilities. One of the most valuable attributes of our LTF is our parent/family networking. Families come together to share experiences and challenges while maneuvering through different facets of raising and supporting a child with a disability. Families deal with all kinds of challenges when raising a child with a disability. In addition, they must navigate the world of Special Education!

One of our primary objectives as a LTF is to bring a variety of speakers to engage with our families. Some of our topics include your child's right to be included with his or her typical peers, understanding the IDEA, and how to assist your child to become as independent as they can be and with a strong focus on self-advocacy. The intent of these training sessions is to empower families to become the best advocates they can be for their child and to also give them the knowledge they need to support this endeavor. I am especially passionate about the transition from preschool to school age. It is the Local Task Force's belief that it is the child's best interest to begin their learning in the Least Restrictive Environment.

We have come a long way since the PARC Consent Agreement, but we still have work to do. We need to continue to honor children with disabilities and the families who started this fight for inclusion. My dream is that someday all children will be educated together and there will be no more segregated classrooms.

To learn more about Pennsylvania's Task Force System:

<https://www.pattan.net/publications/the-pennsylvania-state-task-force-on-the-right-to/>

<https://www.pattan.net/Partners/State-Task-Force>

*Leslie McKelvey, Chairperson & Easton Area, Consumer Representative, Right to Education, Local Task Force 20. The Local Task Force serves as a resource for children with all disabilities and their families in thirteen school districts in Monroe, Northampton, and Pike Counties.*

# A PARENT'S STORY

Dee Barbour, Board Director, The Arc of PA

As a child, I had a heart for the kids who had special needs. I still remember that they either attended a separate school or if they attended my school, they were always in one classroom - never included. They were just other kids that you saw in the same building - like a secret society.

My son Kenyay is now 25 years old. It never crossed my mind that he would not attend school. I did not know about the PARC Consent Agreement at the time. I only knew that Kenyay was benefiting from early intervention and when the time came, he would attend school.



**“ I liked to go to the Pep Rallies, the field trips, watching the basketball games, the cheerleaders and the DANCES! I learned how to do a resume which was very helpful to know when I began job hunting.”  
— Mr. Kenyay Barbour**

## Our Journey Begins

At first, Kenyay attended classes operated by the local intermediate unit. At the time, it was wonderful for him because it allowed me time to figure “this education thing” out. Then I learned about his educational rights and how to fight to make sure his rights were honored. I knew early on that I did not want him in any “secret HIDDEN society.” I wanted Kenyay in an environment where he could flourish and learn at his own pace and in his own way. I wanted teachers who understood him and engaged him in class, not to just sit there drooling on himself or staring off into space all day. I have always felt they needed to earn their paychecks.

## Grateful for Those Who Came Before, But I Needed to Advocate Too

I was grateful for those who fought before me, but it was long before I realized I had to pick up the torch and take it much farther than some in my district had ever taken it before. I had to be comfortable with being labeled as a “troublemaker”, “demanding”, “in your face”. In my mind, the education system has always been designed to allow our special blessings to fall through the cracks. As with any laws that seek to better people society deems unworthy, people are going to assume no one is going to hold them to upholding those laws.

So, it was not easy at first. I kept Kenyay with the intermediate unit until I had no choice but to send him to a regular school. What was being offered would not have engaged Kenyay. He liked to read and was learning to write, yet a multi -disability class was offered with no structure. This was not the best learning environment for him.

I found that once the education system finally realized that our kids really wanted to learn, things changed. Graduating and getting a job was important to our family and it became

important to his teachers. They started to include Kenyay in activities with the other students, instead of just sitting him in the back of the class so he could stare at the other kids.

## When Fully Recognized as a Student, Kenyay Flourished

When Kenyay started high school, which he did 2 years early, he really started to flourish. He was back with his favorite teacher and in an environment where he was doing things and learning skills for life. He loved the pep rallies and getting to see the football players and he remembered taking his sister to school there. The high school programs were some of the best in the city for high school students of all abilities. They got to go out and work in places around the city, they got to do volunteer work, they were encouraged to thrive and be seen. Kenyay loved it, he loved working in City Hall shredding, he got to work in the record store, he found out he did not want to work in any store that had a big window he would be responsible to clean because as he stated, “I don’t do windows!!!” It was awesome.

That did not mean that my work stopped. I still needed to advocate that Kenyay’s program stayed the best it could be, and I had to have “words” with a couple of administrators. I so appreciate that someone before me took on this fight! They fought so that our kids could go to school, that schools did not hide our children in the smallest room in the building. They understood what was at stake. I am so incredibly grateful for them. I am also grateful and proud of every name they ever called me because it meant that I have picked up the banner and made it easier for the next generation of families. I also realize that we cannot back off - we must continue to push, to fight, to challenge the status quo. We must hold our districts accountable!



**The Arc**<sup>™</sup>

*Pennsylvania*

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The Arc of Pennsylvania is affiliated with The Arc of the United States. We have 30 local chapters serving 50 counties and over 12,000 members.

*Season's  
Greetings*



**from The Arc of PA's  
Board of Directors, Staff,  
and many Volunteers!**

**MISSION STATEMENT**

*The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.*