

## President's Address 2010. Are We Still Moving Forward: At the Intersection

Joanna L. Pierson, President, 2009–2010

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I think that, as we determine the building blocks to the future, we need to look at what we have decided in the past. The funny thing about intersections is that we often see them not as stopping points or places to explore new options but as places to plow through to get to the other side. There are numerous intersections or decision points that we must now cross. I talk here about several of these that I think are fundamental for the future of services for people who have intellectual and developmental disabilities.

First, I want to share my current beliefs and how I reached them.

My older sister, Marcia, had Down Syndrome. She was the oldest of a large family, and she enjoyed being at the head of so many sisters and brothers. She was not only part of our family, but she was very involved in our neighborhood growing up.

Education was very important in our family, and Marcia started school at the age of 5. In those days, it was thought that people who had Down Syndrome could not learn to read. Marcia loved sports. So, she had one of us younger siblings read her the sports pages in the newspaper every day. When she was a teenager, she had my brother, Robert do this reading. No one had told him that she could not learn to read. As a result, when he got tired of reading the sports pages out loud every day, he taught her to read.

Marcia was incredibly likeable. As my husband once said, Marcia always made you feel that you were special. I remember once when my brother, Michel, received a call from the bank manager of her bank. Marcia was there with a check she had gotten from Michel because she said she needed money to pay her rent and did not have it. He wrote the check to the landlord. Marcia had convinced the bank manager that it would be better to let her have it in cash. The bank manager was asking—actually demanding—Michel's permission to give it to Marcia in cash. I do not know

about you, but my bank would never make that call for me. Marcia was, without a doubt, one of the most amazing people I ever knew at convincing other people to do what she wanted.

Marcia assigned me my career. She explained that things needed to be fixed so that people could live the way they wanted and be part of their communities. And she made it clear that she would be doing just that, working and being with friends and neighbors and others in her community. She was not planning to become a self-advocate. It was my job as her younger sister to create services and teach professionals so that the system would allow this to happen for everyone.

My beliefs also are affected by the work I have done, work that is the result of my assignment from Marcia. Primarily, I have been involved in designing and implementing service coordination services, family and individual support services, services that people now call fiscal intermediary services, and in systems advocacy. I teach social work classes at the University of Maryland School of Social Work.

I have a number of very definite beliefs. They include the following.

People are much more capable than we think they are.

The vast majority of families are healthy in how they function. All families need to be approached as if this is true until they demonstrate otherwise. We need to realize that we often see families at their most difficult points, when they are seeking assistance or when they are upset about how something is happening, and that they, therefore, will likely not look as healthy as they actually are.

Our role as professionals is about supporting, not being in charge. So we have a responsibility to listen well and not make people ever feel that we know better than them what they should be doing.

We have another and seemingly contradictory responsibility. It is our role in teaching and inspiring. That responsibility is two-fold. The first

part of it involves responsibility to help people dream of more than they currently know is possible and help them expect to live enviable lives. The second part of this responsibility is to create supports and services that people never dreamed they could have. These become services and supports that they love when they use them. Think of this as Steve Jobs and Apple, creating products that we never imagined but cannot live without. A quick definition is in order here.

An “enviable life” is a life filled with purpose and meaning. It is a life with people you care about and who care about you.

We need to use both support and teaching to help people have the skills to live enviable lives. This means we can help someone learn a skill, or, if it makes more sense, we can get someone to support a person so that they do not need to learn that particular skill. We need to do both, not just one or the other.

It is our job to respect and protect government and donated monies. This means that we spend these in responsible ways that we can justify to taxpayers.

The power of each individual is very small compared to that of the government. We need to represent each person and family in a way that equalizes this power or narrows this power gap.

Leadership is about teaching and inspiring and demanding that everyone be better than they think they can ever be.

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## What Are the Intersections?

What are the intersections that we need to determine which way to cross or turn? There are several.

### *Self-Determination*

I believe in self-direction and self-determination. It has had an important role in changing how professionals think so that we view ourselves as providing supports to enable people to choose how they live. It clearly defines our role as supporting rather than defining people’s lives. It forces us to see the world from a different perspective. Nevertheless, it has created a messy intersection with some issues.

One of these issues is that people we serve often are afraid to just step out there. We spent years where I work talking to people about participating in their communities and making individual linkages. Our successes were there, but

they were nowhere near as great as we had hoped. When we stopped and figured out ways for people to test the waters, our successes came much more often. For example, we partnered with the local art center on an art class for people with intellectual and developmental disabilities. Many people took this class. It included people who had been afraid to take an art class for years. After taking this introductory class, they felt much more able to navigate the other classes at the art center. Now, people are involved in the other inclusive art classes there. When Maryland had monies for serving people on the waiting list after years of their waiting for services, we found that people who had said they wanted to move from their families’ homes hired staff and then just sat at home or they did not hire staff and had numerous reasons for not doing so. After talking to people and their families and hearing their fears, we thought an intermediate testing out step was needed. With one person and his family, we started what he called the “Real World.” Once a month, we helped him rent a room at a suites motel. We assisted him and his family to hire staff to come with him. He learned skills to live on his own. He and his family had time to get over their fears as well. We are using this same concept now with a leadership class at the local community college and in creating a business incubator. We need to recognize that people and their families have fears and think about how to overcome these fears.

Another issue that complicates self-direction and self-determination is defining the role for people who do not want to be leaders in their own lives. Do we say they have to do this anyway?

There is a false intersection that we have created by saying that *self-determination* means that everything can be done by neighbors and friends, that there is not any expertise in serving people who have intellectual and developmental disabilities. This has come at a cost. People have lost access to many professional therapies, such as speech therapy, occupational therapy, and physical therapy that could assist them. This is particularly true for young children, whose disabilities could be lessened if they received teaching and therapies. It is important to find a way to balance the two, so that people keep the social interactions of natural supports but still receive the expertise that will help.

There is a need that I hear repeatedly from people and their families for the system to become less, not more, complex while still being fluid and flexible. The view that seems to be part of self-

determination that people with disabilities should receive services in the same ways as everyone else in their communities that can mean contracting with a gym, a support broker, a fiscal intermediary, a tutor, a job coach, a job developer, a housing specialist, and more. As a result, the services become very cumbersome to manage, the opposite of what people say they want.

Another issue that creates some messiness in the discussion of self-direction and self-determination is that its philosophical creation comes from two very different places. The first is individual and family support services, where people have virtually no money to pay for supports and services. The other is people moving from institutions, where anything looks cheap in comparison, which often results in lots of money available to fund supports and services. Clearly, the amount of support coordination for the first is much more intensive, but, ironically, it is difficult for states to consider this because they often view this as administrative support rather than an actual service for the person.

### *Cash Versus Services*

Perhaps the most interesting intersection that the implementation of self-direction and self-determination has led to is that of providing individual budgets versus providing services. Like many other agencies in the early 1980s, The Arc of Frederick County began to provide family support services. Before that, we had provided family support, but at this time we were granted a small amount of purchase of service money to supplement the support coordination that assisted families in locating supports and services in their communities. The evaluations of family support services projects during this period demonstrated the importance of having a support coordinator to help, suggesting that this was at least as important as the provision of money for purchasing.

In 1984, at The Arc of Frederick County, we expanded this service by helping people hire their own staff and acting as an agent for IRS purposes. A key component of this role involved providing intensive support to people in making this work well. What was offered was services not money. We helped the person design a plan. The supports and services in this plan were funded. People saw themselves as receiving supports and services, not cash or an individual budget. Because we found, after extensive discussions with families, that they

believed that being paid to care for a family member changes the nature of the relationship in a negative way, we did not pay immediate family members to do services.

We suffered a significant failure, or learning experience if one wishes to call it that, about a decade later. At this point, in the mid 1990s, we started telling people and their families on a regular basis how much money they had available, reporting their individual budgets to them each month. An interesting phenomenon developed over the next couple of years. People and families began to view the money as part of their individual or family budget, not as part of a plan of services. They began to wait longer to find a new staff person when a staff person they hired left. They began to cut back on the hours of staff time they had felt they needed. Instead, they started purchasing items that they had not been able to afford but that they wanted. They wanted above-ground swimming pools, fancy electronics, and similar items. When one person would purchase something, others would hear and want one as well. We had discussions with people about the use of taxpayer money, but they were clear that they felt the money had been given to them. It began to change the nature of our relationship from assisting people with services to being the people who were monitors or the people who always said "no." It was a difficult time, and we decided that it was not leading to where we felt was the intent of the funds or sometimes even responsible use of government monies. So, we stopped sharing information about budgets and talked exclusively about services instead. We started talking again about planning and implementing those plans instead of individual budgets. It took several years to fully bring the individual planning back to being the core of how monies were spent. I think this intersection is a dangerous one. Turning the discussions to money from services brings risks, as we justify to legislators and others how we spend the funds that are allocated for each person. I think the core of what we should be offering to people is individual services, provided in ways people want, not a budget of monies to spend. This is a where the *Supports Intensity Scale*, developed by the American Association on Intellectual and Developmental Disabilities (AAIDD; Thompson et al., 2004), can provide assistance if we sell the planning component of it as the vital second step after it is used to determine budget levels for each person.

### *Jobs for Everyone, Any Service for Everyone*

There is an intersection to which we keep returning, typically whenever we have a new idea for how services should be delivered. We try to plow through the intersection to ensure that everyone has a job, or self-determination, or whatever service we have determined to be what everyone should have.

If we truly believe that people should be in charge of their own lives, with providers acting in a supporting role, and if we are really listening, then it means we will hear different things from different people. While we should have some limits and boundaries of what is provided (e.g., no institutions, no government monies to pay for expensive vacations or junkets), that is very different than saying everyone must have "X." A key component of people living lives of their own choosing is that we be careful about believing that any of our theories meets each and every person's needs and preferences.

### *Who We Design the System for*

There is an intersection we came to many years ago that I think we need to revisit. We often talked about moving the system to respond to people who have behavioral needs and people who are very vocal in their complaints. It is important to respond to the issues that cause people to have behavioral needs, and many good ideas came from this. People who complain can assist us in rethinking what we do. However, we went a step further and designed almost all of our new ideas for the entire system around their desires. I believe that this is a crossroads that needs to be reevaluated.

Unfortunately, some of the people who complain not only get the biggest budgets and get everything they demand, but they are also sometimes the people who want to devote their lives to managing their son or daughter's lives. Much of what we say about self-determination has been designed based on this desire and leads to a system where families hire the staff and act as support brokers. From everything I hear from people I serve, the group that wants all this control and all the work that comes with this is a very small minority.

Early in my career, I asked a group of self-advocates at the provider agency where I worked to do a presentation at an annual staff training to tell us what they thought of the services they were receiving and what they wanted in the future. The most powerful part of their talk was when one of them strongly criticized a service and then immedi-

ately afterwards, he said, "It is okay, we know you are trying very hard," and the rest of the group strongly agreed with him in this. The majority of people we serve do not want to hurt our feelings, particularly when they like us. Most people tend to give higher satisfaction scores than they feel.

I worry about this vast majority of people who are sitting politely and silently by. I think we all would agree that they should not have "lost lives." I think the service system must be designed so that they receive excellent services that result from listening to how each and every person prefers his or her services to be delivered.

When I talk to families, they often say that they want a sister, brother, parent, or spouse relationship with their family member, not to have to be spending their time making their services work. What people say they really want is a system that is flexible, easy to understand, and meets their or their family member's needs. They want someone who listens. They want to have staff they like. By *flexibility*, they mean that people get what they need, when they need it, delivered in ways that they prefer. I hear again and again that people get tired and do not envision themselves being responsible for making their services work forever. They see providers as having a very clear role in operating and coordinating individual services.

My comments on this intersection may seem contradictory to my earlier statements that self-determination is important, but they are not. What I am saying is that it is important that we not just transfer all responsibility to individuals and their families. Our role as providers is to give people choices in how people receive their individual supports and services. Provider agencies will often end up providing a significant amount of support. When I look at the individual services we provide at The Arc, we work to make sure that what people and their families agree to do is sustainable over the long run. We revisit this often with them to ensure that what they agreed to is still possible for them. I also believe that many people will choose more traditional services than we, as an agency, provide, and I believe those options should be available.

### *High-Cost Services Versus the Waiting List*

There is an intersection that exists where people on waiting lists sit with little or no services. Across from this are the people who receive residential and employment or day services, what



we have traditionally termed *full services*. Because Medicaid waivers fund much of these services, and many of these waivers state that people are entitled to everything they need, many people have very expensive services. This crossroads is the intersection of the “haves” and “have-nots.”

It is difficult to believe that the political will is such that everyone who needs and desires services will receive them at the level of cost that currently exists in our service systems for these full services. We have to make choices, and these are difficult because the most powerful voice is the voice of provider agencies, not of individuals and families, particularly not of individuals who are awaiting services. It is important to create solutions that enable service costs to change and rise or fall as people’s needs change. This is not the same as saying that providers need more money, which we have confused it as meaning. Part of this involves providing less costly support to people early on so that they may never need costly residential services but having these residential options available if and when they do require them. More fluidity in the system might actually drive down costs, if people really believed that these services would be available when required by them. Part of the success here also involves seeking new innovative solutions: for example, significantly better utilization of technology.

Some current solutions involve creating new waivers that only allow new people entering the system to have a small amount of supports. Often, states tell people that this is called self-determination, but it is a perversion of what self-determination was supposed to be. Forgetting how close this comes to being an excellent example of George Orwell’s doublethink in his novel *1984*, it is, more importantly, not a fair solution. People on waiting lists and people who have no services have been relying on their personal connections for years. When they are asking for help, it is not a matter of us going in and telling them to use their networks better. It is about increasing services. And again, it is about innovation in our services.

Part of the problem is that the burden of financing needs to be shared differently. Nonprofit agencies must view themselves as part of finding at least one solution, if not multiple solutions that lower costs per person and still allow agencies to provide excellent services. This is not to suggest that governments do not have a clear responsibility to people with intellectual and developmental disabilities, for they need to be willing to support innovative solutions and not drown them in

paperwork and rules. Governments need to streamline their own processes as well. One of our problems as a service system is that we have moved well beyond a model where costs are reasonable. When I look at costs of services in my state, which is often listed as the wealthiest state in the nation, the average cost of services is very high compared with the median income in the state. I think we need to see that as an issue that we have to solve.

We must take on the challenge of creating sustainable costs in our service delivery system that allow everyone to be served.

### *Service Coordinators Versus Support Brokers*

We are coming to an intersection where we will be deciding whether to have service coordinators or support brokers, or both, and define one as working for the state and one as working for the person. The discussion centers on whether it is a conflict of interest for someone to work for both the funder and regulator as well as for the person.

We are at this intersection because of problems the service system has in meeting people’s needs and the inability of service coordinators to fix these. Our solution for system problems has been to blame the service coordinators. We have not blamed the funders or the providers nearly as much. In fact, the issue may be that we have not invested all we said we would in service coordinators. We have not provided them with enough authority. We have not trained them sufficiently. We have not made it clear that they work for the person as well as the state and that they work for the person first and their role for the state is secondary. We have punished rather than rewarded them when they advocate strongly and well.

It is still important that service coordinators be viewed as able to work representing both the state and the person. Government is very powerful. Because of this power, it automatically has an incredibly unequal relationship with people and their families. To equalize this, states need to invest in service coordinators whose job it is to be the translator from both directions, the person and the state. States need to invest in service coordinators who assist people served through an increasingly complex system. States need to invest in service coordinators who can help the state really listen to individuals’ ideas, needs, and preferences. They need to invest in service coordinators who they believe have the taxpayers’ interests at heart along

with those of people needing services. States need to invest in a system of service coordinators who represent both the state's and the person's interests so that government can trust that the decisions made are in the best interests of both the state and the person as well as helping government be more forward looking about how much these two interests do have in common.

Alternatively, the role of support brokers should be to assist people who want individual support in locating nontraditional services and in operating them. They should be responsible for making services work on a daily basis. While their interests should be as advocates for each person they serve, their primary role is to assure that the supports and services are working each and every day. They are really providers without walls and should be part of nontraditional provider agencies. They also should have the ability to act as fiscal intermediaries as part of their role, rather than states investing in the expense of funding separate fiscal intermediary agencies. Most people and families I know talk about keeping the system simple. They feel professionals overemphasize the potential for conflicts of interest among support brokers, fiscal intermediaries, and provider agencies, thereby creating a system that is too cumbersome, one that results in their having to devote too much of their time to making services work and not having enough time to simply living their lives.

People and their families talk about fluidity of the system. This implies receiving what you need when you need it. This implies having service coordinators that believe in the importance of services, that view themselves as responding to how people want to live their lives, that provide ideas and support and expertise to enable people with intellectual and developmental disabilities to live enviable lives, and that understand the importance of families in all of our lives.

People receiving excellent service coordination often say that they cannot understand how they would ever manage to live without it. I remember one mother saying that, as terrible as it sounded, it was a gift to know that she could someday die because she knew there was a system to keep making everything work for her son. I think this tells what the concept is capable of creating, what the service can be if we invest in it properly as a system.

Listening to people also leads me to believe that complicated systems diminish the power of the person rather than increasing their power. Overly complicated systems increase individuals' reliance on others

to help them. Separating out service coordinators, support brokers, fiscal intermediaries, and providers into four distinct groups, with often multiple providers creating many more groups for people to deal with, leads to an increasingly complicated and cumbersome system. This intersection needs to become simpler if people are to actually have power.

### *Leadership*

Everyone is discussing the intersection we face with many current leaders closing in on retirement and the general turnover of leadership in the field. The crux of this intersection is determined in how we answer the question, "Do we hire people who come with more business-oriented approaches as the management literature suggests is needed, or do we continue with a more traditional nonprofit approach?"

Many people I hear discussing this, talk about the second option, keeping vision as more than a business decision. I want to talk about how to make this work because I think this is the turn to take rather than taking the turn to become like businesses.

If we older leaders really want to turn over the keys, we have to come to grips with the fact that, as for all successful people, we believe in our hearts that we can do everything best. In addition, in our field, we have a tendency to be somewhat self-righteous about our beliefs. This is apt to lead us to try to hire clones. Unfortunately, this will not help pass leadership on to the next generation or to people with intellectual and developmental disabilities as the next group of organizational leaders.

It has worried me for a while that we do not seem to think we have people ready to take over the leadership of the field. It is interesting when you realize how many of us became leaders when we were relatively young. This implies that people trusted us and provided us with what was necessary to learn to become leaders. It alternatively implies that we just took over and started what we thought was needed. That still suggests that we have not enabled others to do that by providing the opportunities and teaching.

The model used in academia is of interest here. Professors work very hard to create the atmosphere, teaching, and support for their students, particularly graduate students, to move on and collaborate and compete with them at other universities. They actively impart knowledge, not worrying if they are helping competing universities where their students may work after they receive their degrees.

With that in mind, what could we be doing in the practice sector to create more leadership? We have to create active teaching models. We have to not only work on creating organizations where active teaching and learning of staff are part of the culture, but we have to create organizations that actively recruit and create an atmosphere where staff want to learn. The model used by organizations where professionals work is very applicable here. Their model of supervision involves providing structured opportunities for observation, then discussion of those observations, then practice by the person, and then guided discussion of that practice. It additionally involves thinking through their actions by looking at their practice models and theories as actively guiding these.

Creating expectations is part of creating leaders. Being sure that people know that they can talk to anyone in the organization, rather than being forced to surf the bureaucracy for answers, creates leaders. Providing “opportunities” meetings where people are expected to tell the director what is working and what needs to be changed and never punishing anyone for speaking up, creates leaders. Telling stories that encourage people to challenge themselves does this as well. I went back to school to get my doctorate when The Arc of Frederick County had increased in size to about 120 staff because I realized that no matter what I said, the size itself made it hard for people to think I meant it when I said they could disagree with me. I thought that professors and fellow students would have no problem telling me when they thought my ideas were bad. Telling this story to staff has been one of the most important ways I can continually convey that I need to hear other ideas and viewpoints.

To create leaders, we have to move beyond the current business model, which has not been terribly successful for many of the businesses run by people with MBAs in this country recently. This also probably involves never calling anything teams because they are much more about process than action or implementation. It requires action planning to enable staff to actually make things happen for people we serve.

It is important to address the deadening impact of our systems. The terrible impact of the vast amount of paperwork on creativity cannot be underestimated. Like teachers teaching to the test, providers working to simply meet regulations will not result in leaders. Alternatively, there is a resulting impact on individual staff creativity and advocacy when agency leaders are continually

involved in systems advocacy. This is true not only because it lessens the burden of work that encourages not thinking but because it communicates that everyone should advocate changing the rules when they do not work. This is a very powerful message.

Last, part of being a leader is not simply giving people what they want; that is, not just doing surveys to figure out your next step. In 1984, I had the opportunity to implement a service that I had wanted to do ever since I started my first job. The state-funding agency came to me about a person who needed services. He had lived in an institution for a short time, but his mother had complained so much to the governor that he had been allowed to move home with a provider agency hiring staff to provide services in their home. The provider was stopping services because the mother called the governor about once a week to complain about the agency and the staff they hired never lasted more than a few months. In fact, it was worse than this, because the governor himself would actually call the agency and yell at them about once a week. The provider had enough and was stopping services. As a result, the state-funding agency was desperate. I said that it was clearly a conflict of interest for us to do service coordination and provide direct services, but I had an idea of what might work. I said we would provide very intensive service coordination and act as a funding conduit. The service coordinator would help the family hire and fire their staff and in any other way the family wanted, such as training staff. However, the family would have control and be the employer of their direct support staff. Ultimately, the family would be responsible for making it work because the service coordinator could not be available to substitute if someone did not show up for work and we did not have any other staff who could do this either. I was fortunate because the funders were frantic to have this solved; the governor was yelling at them as well, and no other agency was interested in providing services. We immediately started this model of providing very intensive service coordination and acting as a funding conduit. The mother called the governor the first week when I refused to pay her staff because she refused to send timesheets, which had been part of the agreement. However, after this, she became extremely pleased with the services, as was the rest of the family. The two staff members who were there at the start and had been expected by the previous agency to quit remained for over 7 and 14 years, respectively. It was a service that the family had never thought of, but it met their

needs in a way that nothing they had thought of would. If one thinks about success in the business world, innovators often demonstrate quite well that leaders should create the future before anyone has thought of its existence. We need to encourage younger leaders in our field to do this as well.

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### Conclusions About the Future

So what are the building blocks of the future? Are we still moving forward? We have made tremendous strides in the last half-century in communities' acceptance of people with intellectual and developmental disabilities. There is inclusion in many neighborhood schools. There is a belief that all people have a right to an education. There is government money to support people living in their communities, either in small residential services or through individual and family supports. Many more people are employed in their communities, and there is a public belief that adults with intellectual and developmental disabilities should have services when they leave the school system. Colleges are beginning to accept small numbers of people with intellectual disabilities into their courses and degree programs. Clearly, there is still more work to be done in all of these, but we have moved forward a long way in the past 50 years.

We have not moved as far in people being intertwined in the social life of their communities or having sufficient friendships beyond their families, as well as enjoying intimate relationships. This is perhaps the most difficult to create because fostering this requires us to be intensely engaged in our communities ourselves. It now becomes even more difficult because the very nature of community is changing, becoming more based in technology and less in personal presence. Our job in the next phase of our work then is to successfully engage people we serve in both of these communities, strengthening the physical communities and connecting to and designing the virtual communities for meaningful participation.

To keep our momentum in moving forward, there are three avenues that we should pursue based on and in addition to addressing how to move through the intersections that I have already discussed. If we wish to continue to move forward, then we should be thinking about sustainable lifestyles for people we serve. We need to build a

system that is affordable for government to fund, is not overly cumbersome for individuals and their families to manage and maintain, and does not overly rely on the lifelong participation of individual volunteers but still creates supports and services that encourage people to become part of their communities and communities to become part of their lives.

Another important building block for the future that we need to pursue much more aggressively is technology as a supporting tool in assisting people in participating and being more independent as well as replacing staff, which is one of the building blocks of our past that we now have in shorter supply. Part of this look at technology involves figuring out how "community" itself is changing with the Internet and how to include people with intellectual and developmental disabilities there in terms of employment, social networking, and learning.

The third building block is listening carefully to each and every person with an intellectual or developmental disability and his or her family and using this information to allow for more than one option for supports and services. Each of these services must meet certain values in terms of supporting people in living enviable lives in their communities, but part of imagining the future is believing that new leaders will create new and better options and that encouraging this flexibility creates enthusiasm and energy and will solve the issues that we still face.

So, to answer my own question, we are still moving forward. We will continue to need to do so into the future.

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### Author:

**Joanna L. Pierson, PhD** (E-mail: [jpierson@arcfc.org](mailto:jpierson@arcfc.org)), Executive Director, The Arc of Frederick County, 620A Research Dr., Frederick, MD 21703.