

People First of Missouri Position Statements

Advocating for Rights and Respect

Advocating for Self Determination and Decision Making

Advocating for Quality Services and Supports

Advocating for Quality of Life in Our Communities

Approved by People First of Missouri Steering Committee

November 11, 2018

People First of Missouri (PFMO) is a self-advocacy organization that was formed by, is run by, and exists for people with developmental disabilities in the state of Missouri. Our membership consists of local affiliated chapters. People First of Missouri is a non-profit organization that promotes equality for people with disabilities so they can live the life they want in the community. To learn more about who we are, visit our website at www.missouripeoplefirst.org.

PFMO Position Statement: Advocating for Rights and Respect

What we see and know

Disabilities are a normal part of the human experience, but many people still do not understand us. Every single disability is different, looks different, and can vary from one person to another. People seem to think that because we have a disability we need to be talked to differently, such as slower, or sometimes they are simply afraid to talk to us. We see that people with disability are often treated as children. We see and can feel the judgement within our communities, with “feeling sorry for us”, separating us from others. Some people try to control us by giving us medicine or admitting us into segregated places. We see that some staff, family, friends take advantage of us and treat us poorly. We see that not everyone wants to hire us for work. We see that our community is not always accessible, such as sidewalks with curbs, restrooms with narrow doors, and need for more ramps. We see that transportation is a huge issue.

What we feel

We feel our right to make choices is not being respected. Choices are made for us, not by us. We feel that if we are making a dangerous choice that someone should step in but otherwise we should be allowed to make our choices. If we make a bad choice, it shows that we are just like everyone else. We do not like it when we are treated as children. We feel that sometimes we have to change our thoughts, beliefs and who we are as people to be accommodating for support staff. Disabilities can be seen or not seen so we feel that people should respect everyone and treat them as equals.

What we want

We want inclusion and to be treated as equals. We want children with disabilities to be taught from a young age how to make their own decisions. We want to be treated as the adults we are, not the developmental age we are perceived to be. We want laws changed to protect our civil rights to privacy and decision-making, just the same as any other human being. We want to be listened to and asked what we need and want. We want to be treated like anyone else, given real choices, and respected after the choice is made. We would like those who support us to get to know us as people, not as disabilities and learn how we communicate so they get to know us for who we are. We would like to be able to have boundaries with staff, family, etc. so we can have good working relationships. We would like equal pay and benefits in all employment settings. We want our communities to have accessible parking spots, more accessible rooms in hotels, more accessible sidewalks and ramps. We want our community leaders to learn more about us as people with disabilities and treat us with respect.

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PFMO Position Statement: Advocating for Self Determination and Decision Making

What we see and know

- We see that some people are assigned guardians/conservators without a say in the process.
- We see that some people who have guardians/conservators don't legitimately need them.
- We see that some people do not have access to the supports they need to make decisions about their lives.
- We also see that when people access support services through agencies, their rights to live lives of their own are limited by rules, regulations, and bureaucracy.
- One People First member points out she has a conservator, a Public Administrator, who "serves" over 300 people. It's virtually impossible for her PA to be individually attentive to the best interest of those she's supposed to serve.

What we feel

We feel that, given that the guardianship/conservatorship process can take away someone's rights to make all or part of their own decisions, the person affected should be directly involved in the process.

Another member points out that because he gets support services through an agency, he can't just decide to go out in the community to do something he wants to do with support—unless it's been written in his plan and is prior authorized by the state bureaucracy. He feels controlled.

Systems are failing to "walk the walk". They are constructed with too little regard for and too little input from the people they're supposed to be supporting and respecting. We feel these systems are failing people who should be their beneficiaries.

What we want

- We want to make our own decisions with the support we need to make those decisions.
- We want guaranteed legal protections, including the right to select our own legal counsel, and to be present in court when guardianship/conservatorship is being considered.
- We want more control in the decision making process about our supports and services – both at the individual and systems level.
- We want easy access to appealing decisions – getting help with advocacy when we disagree with decisions made about us.
- We want a service delivery system that will respond to our decisions. We do not want a system that makes decisions for us.

PFMO Position Statement: Advocating for Quality Services and Supports

What we see and know

- We see that services and supports often aren't responsive to our desired lives. They often aren't timely, reliable, available when needed, or provided in a flexible way. One member said, *"We have to live on agency or staff time, not ours."*
- We see services and supports provided in a way that is not respectful and confidential. One member shared the phrase *"You work in my home, I don't live in your work place"* which summed up how people felt.
- We see that some who provide support do not have a good understanding of *disability*, and what it means to support us. There is a big difference between supporting us and controlling our lives.
- We see too much abuse and neglect with the providing of services and supports.
- We see that getting and keeping services and supports is often complicated. One member said, *"The Utilization Review (UR) process takes too long to get needed changes in a timely way."* We are often part of this complicated world and shouldn't have to be.
- We see that qualified support staff are hard to find and keep. Staff are often under-trained, under-paid and without benefits – so they leave. One member said it this way, *"Finding and keeping good staff is a big thing."*
- We see that some support staff are unreliable, under-motivated and are only there to have a short-time job – not to serve the people they are paid to support.
- We see that there are too many steps to get people hired, especially with self-directing services.
- We see that there are challenges using "natural supports". One challenge mentioned is that family members are sometimes expected to take on the *caretaker role*. One member said, *"In the UR process, use of natural supports first can cause family stress. My wife shouldn't be looked at first as my caretaker."* Family members may provide some care but they are not substitute caretakers.
- We see that services and supports are often developed without us.
- We know there is a difference between self-directed driven supports and provider driven supports—it's not so much about who is providing the supports, as it is about who is driving the supports—the individual receiving the supports should be driving them.

What we feel

- We don't like feeling only partially in control of the services and supports we get.
- We feel frustrated because of restrictions on services and how complicated the service systems are.

- We don't like that services and supports are often provided in a way that is convenient for staff and not for us.
- We feel angry that people with disability are sometimes abused and neglected by those who provide us support.
- We feel angry when we are disrespected by some who provide us support.
- We don't like being excluded from decisions about services and supports that affect our lives.

What we want

- We want services and supports that truly assist us to have the lives we want.
- We want to use "natural supports" as much as possible, but not as a substitute when paid supports are needed or more appropriate.
- We want services and supports that are easy to understand, easy to access, available when needed, responsive to our individual needs, flexible, and are executed seamlessly.
- We want a system that supports us to live in a place of our own, with whom we want to live.
- We want more and flexible transportation to get where we need to go.
- We want services and supports to be safe—to be free from abuse and neglect.
- We want to be at the table when decisions about services and supports that affect our lives are being made.
- We want more control over our supports and services at all levels, including who provides them.
- We want to continue to self-direct our services—to have a direct say on who, how, where and when they are provided.
- We want to be able to make decisions to make things work with those who support us directly.
- We want services and supports to be offered in a mutually respectful manner.
- We want provider agency leaders to equally listen to and hear us, not just their staff.
- We want support staff to listen and understand us, so they can support what we want and need.
- We want good, qualified, dependable support staff to be paid a competitive wage with benefits so that we can recruit and keep them.
- We want support staff that are trained to support us. We want "real," hands-on, paid training for them and service coordinators.

PFMO Position Statement: Advocating for Quality of Life in Our Communities

What we see and know

- We see that our quality of life is limited by a lack of opportunities in transportation, jobs, things to do, and clean, safe places to live in the community.
- We see that many towns have little or no public transportation and taxis are often not accessible.
- We see that existing disability-specific transportation services put many strict limits on where, when, and how we can use them.
- We see that having a job is not just a way to make money to pay bills. It is also a place to connect with other people and make friends.
- We see that it is hard to find jobs with employers who are patient while we learn new skills and willing to let us have accommodations we need to do the work.
- We see we need more job training to be able to find jobs where we can move up the ladder to higher pay.
- We see that many people still need benefits counseling so they can learn how to work without losing their public benefits and services.
- We see that there are not enough affordable options for places to live.
- We see that we need both money and transportation to access things to do in our communities.

What we feel

- We feel community should be for everyone.
- We feel frustrated that we often are stuck at home. If we cannot get out into the community, we cannot be a part of it. We feel our lives are more limited by transportation issues than any other.
- We feel trapped by the rules our service providers make that keep us at home. Some of our support staff are not allowed to leave town for work, which means we can't travel either. This means we can rarely see or experience the world outside our own towns. This restricts our civil rights.
- We feel stuck in low-paying jobs. We also feel unsupported and lack needed training to keep learning work skills.
- We feel it is difficult to find a clean, affordable place to live.

What we want

- We want to be included in the world around us, not excluded.
- We want access to the community. In order to do this, we must have a way to get there.
- We want more public transportation options that are simple and safe. We want more funding for accessible disability-specific transportation services and taxis to be accessible for wheelchairs.
- We want Missouri to expand the travel distance limit for support staff and create consistent rules on this for all provider agencies to follow.
- We want jobs in the community to be a first choice to try, not the last. We want information about jobs and careers in the community and help to find them. We want one-on-one job coaching and employers who will be flexible with simple accommodations we need.
- We want opportunities to “move up the ladder,” take on new responsibilities, and earn more money as we learn on the job.
- We want more access to benefits counseling and to learn about ABLE Accounts, Special Needs Trusts, and other tools we can use to earn money and not put our public benefits in danger.
- We want protection from over-controlling guardians, family members, friends, providers, or staff who limit us from joining groups or going out into the community.
- We want more clean, safe, and affordable places to live in the community.
- We want training and support for families, friends and guardians to support us to access community life.