

## **Personal Assistance Services (PAS)**

### **INPUT, INFLUENCE, AND IMPACT Texans with Disabilities Driving Advocacy**

#### ***Introduction:***

The Coalition of Texans with Disabilities (CTD), with the help of a variety of organizations and advocates, developed three online surveys to collect data on topics that directly affect the disability community. Statistical and qualitative data was collected from January 30, 2015 to March 13, 2015 on disability employment, early childhood intervention, and personal attendant services by CTD's developmental disability policy Fellow. CTD's fellow is part of Texas Council for Developmental Disabilities grant-funded program that supports a policy-focused staff member to develop professional experience on disability issues.

CTD estimates as many as 20,000 people with disabilities, their families, and supporters received (multiple) notifications of the availability of the surveys and their importance for the policy Fellow's research. Outreach was conducted via word-of-mouth, social media, newsletters, and online methods. Many of CTD's partners were gracious in sharing the outreach efforts.

Unfortunately, the numbers of submitted surveys were extremely low and not statistically significant. Therefore, inferring any conclusions or contrasting the survey data with nationally collected statistics would be inappropriate. However, the open-ended questions provided invaluable input and insight for CTD staff members during the 84th Texas legislative session. These responses helped CTD staff members to understand individual challenges and omnipresent barriers that Texans with disabilities face on a daily basis.

Respondent answers have been edited minimally by correcting spelling errors and formatting. All respondents were anonymous and responses have been randomized to protect each respondent's privacy. Several respondents filled out paper surveys (Appendix A) or were scribed by the policy fellow.

#### ***Current Situation:***

Personal attendant services are the cornerstone of independent living for approximately 150,000 Texans with disabilities and the elderly. Personal attendants are the key to cost-effective community services and help individuals with disabilities achieve a greater degree of independence than they could on their own. Community care workers assist their care-recipients with a wide variety of daily tasks, allowing them to avoid unnecessary, expensive hospitalization or institutionalization.

However, there are significant challenges in hiring, training, and retaining consistent and quality care personnel for many Texans with disabilities. These challenges have created a shortage of personal attendants that have made it difficult to support and expand community living options. Simply put, there is a crisis in community care.

**Survey Data:**

The personal assistance services survey (Appendix A) consisted of 30 questions to collect quantitative and qualitative data. 29 Texans with disabilities responded to the survey questions and provided useful insight into how their personal assistance services are delivered, how turnover and inconsistency affect their daily lives, and solutions to the various problematic issues and barriers to consistent and quality care for this vital service.

**The Basics:**

**Who Provides your Personal Assistance Services?**

- 60% of respondents stated that their Personal Assistance Services (PAS) were provided by a **Consumer Directed Services (CDS)** provider, 25% stated an **agency** as a provider, 4 stated **private pay**, with 1 person receiving services through **private insurance**. 5 respondents chose more than one answer.

**Where do you receive services?**

- 63% of the respondents stated that their attendant provided services **at and outside of their home**; 37% stated that they received services **in their home only**.

**Hours received?**

- 80% of respondents stated they **received enough** attendant care hours to meet their needs; 20% stated that they **did not**.

Responses	10	5	4	3	3
Hours of PAS per month	4.5-60	96-128	160-173	216-300	660-720

**How many personal attendants do you utilize?**

- 74% of the respondents utilized **more than one attendant**, while 26% had **only one attendant**.

Responses	9	4	3	1	1	1
# of Personal Attendants	2	3	4	1-3	>5	7 (part-time)

**Relationships?**

- 100% of the respondents stated that they had a good relationship with their personal attendants.
- 100% of the respondents stated that the relationship between themselves and their personal attendant was very important.

**Retention?**

- 52% of the respondents stated that they **easily retain attendants**; 48% stated that they **do not**.
- Respondents' answers varied greatly on how long their longest tenured **current** personal attendant had worked for them.

Responses	8	4	3	5	2	4
Current PA tenure/years	< 1	1 - 2	2 - 3	3 - 4	4 - 5	> 5

- Respondents' answers varied greatly on how long their **previous longest** tenured attendant had worked for them.

Responses	9	8	1	2	4	1
Previous PA tenure/years	< 1	1-2	2-3	4 - 5	>5	n/a

**Pay?**

Responses	3	14	5	2	1
\$/hour	< \$9.00	\$9.00 - \$10.00	\$10.00 - \$12.00	\$15.00	\$32.50

- 83% of respondents stated that the hourly rate of pay for their personal attendant was **not enough**, 9% stated that the amount was **sufficient**, while another 9% stated that the question **do not apply** to their situation.
- 83% of the respondents stated that they felt they **would receive better personal attendant services if their attendants were paid more**; 17% feel they **would not** receive better personal attendant services.

**Gaps in Services?**

- 52% of the respondents stated that an unscheduled absence of their attendant has **affected their health or their employment**; 48% stated that it **had not**.

**Trained Caregivers?**

- 65% of respondents stated that their personal attendants **did not have a healthcare services background**, 27% stated that their attendant **did have a healthcare services background**, and 8% **did not know**.

- 71% of the respondents stated that **they trained** their personal attendants, 8% stated that the **agency trained** the personal attendants, 4% stated that the attendant was trained in a **college or university**, while 17% stated that they **did not know**.
- 60% of the respondents stated that their personal attendant(s) were **not trained** in providing services to people with disabilities, 36% stated that their attendant **was trained**, and 4% **did not know**.

#### **Attendant Transportation?**

- 92% of the respondents stated that their primary personal attendant used their own **personal transportation** to the respondent, 4% stated that their personal attendant used **public transportation**, and 4% stated that their personal attendant lived with the respondent and **did not need to travel**.
- 62% of the respondents stated that their personal attendant's choice of **transportation never caused service problems**, while 38% stated that the personal attendant's choice of transportation **did cause service problems**.

#### **Making ends meet?**

- 64% of the respondents stated that their primary personal attendant **had another job**, 24% stated that their primary attendant **did not have another job**, and 12% **did not know** if their attendant had another job.
- Of the respondents who stated that their attendant had another job, 70% stated that their primary attendant had a **part-time job**, while 30% stated that their primary personal attendant had another **full-time job**.

#### ***In Their Own Words:***

##### **Respondents were asked how personal attendant turnover affects their life.**

- a) "The attendant is for my 15 year old daughter who has cerebral palsy and autism. If our family lost this benefit, we would fall apart. It is too stressful caring for our daughter. She requires full time help with every day activities. She cannot be left alone, she does not speak, and she's still in diapers."
- b) "I try to hire people who are in college because they are motivated in life and typically do a great job. However, they graduate or get higher paying jobs and leave. Then we have to hire and train new people."
- c) "I have tremendous difficulty retaining attendants because the pay scale is so low it does not attract personnel who are appropriately trained to handle all my son's disabilities, particularly autism. This is the most difficult reason why attendant care services have not been particularly

helpful. It impacts are lives tremendously because we have no support in our home for our child or for the community. It isolates us both physically and socially. When we have emergencies we have no back up to help us as we are so isolated by our son's numerous challenges that we literally do not have support in the community and personal care attendants are vital for us in that respect as well. It has impacted my ability to retain employment and our entire families emotional and physical well-being has been hindered by this. Also one family member had to be hospitalized for PTSD due to the stress of having a child with so many challenges who was starting to get aggressive."

- d) "Hard to get to know the people that come in to sub."
- e) "It is hard trusting someone new with my adult son and having someone new in our home. It causes a lot of stress, and it is hard to find someone willing to work for the rate we are allowed to pay. It is difficult to train new people to help our son with taking a bath, shaving, etc. Some people don't feel comfortable providing that type of care."
- f) "It is hard because I can't get adjusted to new people very well because they do not know about me and my daily needs. It is also hard because each new person needs to fill out all the paper work for services employment and get approved which is confusing and takes a long time."
- g) "I have had difficulties with my agency finding and retaining personal attendants to work a few hours on the weekends. Providers don't show up, come late, and lack motivation and basic skills to prepare meals and help with common tasks. This situation has made me anxious about living independently. I have to ask friends and neighbors to come to my rescue just so that I can eat. I don't like having to ask others because I have unreliable assistance."
- h) "They often leave for better, higher paying jobs or they have health or transportation problems that interfere with their ability to work. Yes, it significantly impacts my life. The agency I'm with does not have a big pool of attendants to pick from and many times the substitute attendant has several clients to attend to and you end up waiting several hours before they show up to help you. This means you have to wait to go to the bathroom and you don't eat or even get out of bed for hours until they get there."
- i) "It makes me do more things for myself that take longer which causes me to be exhausted all the time, and I have to depend to family & friends. All this gives me a sense of not having control of my own life. It also makes it harder to work because I need to take time off to conduct interviews and/or train new attendants."
- j) "I've lost many very good attendants because they simply had to find a job that paid enough to live on. When I lose an attendant it can take 1 to 3 weeks to replace them and an additional 2 to 4 weeks of training before a regular schedule can be established again. This continued cycle disrupts my life and keeps me from being able to commit to anything that requires a schedule."

- k) "The schedule of the attendants can get in the way of their providing services when we need them. This makes it very hard to depend on a regular schedule of attendant care."
- l) "It is hard to find someone else to come in and help me when we are in between attendants and my mom and I have to retrain someone else to help me with my routine."
- m) "Even through CDS PCS services only can offer \$10 per hour wage; so at this low wage most attendants are unreliable and irresponsible."
- n) "No, but I have had a hard time retaining good ones."

**Respondents were asked how long-term personal attendant retention affects their life.**

- a) "Makes my life more stable."
- b) "As I said, our family cannot lead a normal, functioning life without having in-home help for our disabled daughter. Our other child would suffer greatly, our family life would not happen; we would most likely break up. Our daughter is so difficult at times; it is a wonder we are still together as a full family."
- c) "In the past I struggled with PA retention but have been really lucky the past 16 years. In the past, I didn't have a back-up plan or a good one. I didn't provide as many extra perks to the job such as bonuses, travel, paid time off, etc. I feel I have improved my management style and did my best to respect my attendants' time. I've done my best to not let retention issues affect me but again it's about having a back-up or at least a back-up plan so it doesn't impact your life as much."
- d) "My attendant and I know each other very well. Going through all the necessary tasks is routine by now, which makes it easier for both of us."
- e) "PAs are important and reduce barriers to independent living."
- f) "The part-time attendant that has been with us for a long time gives us peace of mind. We trust her, and that is the most important factor."
- g) "I can count on them. I wish I can pay them more. They are very reliable."
- h) "Having a personal attendant that stays for a long time makes my life easier in every way. I have help that I can count on to get a shower, take my medicines and eat. They are also my companions and I trust them completely. They improve every part of my life and make it possible for me to live at home."
- i) "Without regular reliable attendant services that I am comfortable with, I wouldn't be able to perform at my best, reach my work and personal goals or take risks for new environments and challenges, essential for growth as a person and role changes in life. My life is blessed because of the tasks attendants perform and the lifestyle it allows. My choices are reflected in my environment instead of my life being situated in someone else's environment and schedules. It allows equality and independence vs. charity."
- j) "Makes life more efficient."

- k) "For me it is that I pay a rate of three times that of most state programs. By taking care of him as best I can and fairly he does the same for me. Creating better outcomes and stability for us both."
- l) "At first I only had 1 and then added another. Then my brother and his wife hired more, including guys because I would like working with both males and females."
- m) "If I don't have a good attendant, I lose my focus and motivation. I get a terrible outlook and I didn't want to participate in the community. A good attendant that can keep things clean can help thrive and not just survive."

**Respondents were asked to relate a specific instance where the unscheduled absence of a personal attendant directly affected their lives.**

- a) "Our attendant is very reliable. But there are 3 instances that stand out when she could not make it to work. When that happens, we have to change the whole families schedule to make sure one of us is helping each child in the family and one of us is still trying to hold a job down to pay the bills. This usually means our typical kid loses out. No one is there to help her with the things she needs. This is very hard and not fair. We cannot provide any type of normal life for our selves or our normal kid if we did not have help with our disabled child."
- b) "When one of our summertime attendants had to have surgery, I had to work from home. I was very fortunate that my boss allowed me to work from home, but that limited my son's activities."
- c) "If my attendant can't be here I don't have help to eat and take my medicines and that hurts my health. I also do not have anyone to help me get changed and that is also bad for me."
- d) "I have had to call friends to meet me at the grocery store to help. I have had to rearrange meals and mealtimes when caregivers fail to come."
- e) "When I was working, it meant I would be going in late or not go in at all. This affected my pay, sick leave and completing my work tasks."
- f) "Sometimes when my attendant calls in at the last minute or she doesn't come or call, I have to go to work late and w/o eating all day until I get home and I can take my time. Then, there are other times when I don't want to struggle with getting dressed and go w/o eating."
- g) "Certain daily living tasks stop. Since the tasks are daily - that's a huge problem. Life goes on and I'm not ready then. It's the same as having a car dead battery or the water cut off. You just can't get the day going as it needs to. Everything piles up as a problem."
- h) "As an advocate and a RAS I have had to avoid situations that would require me to be present somewhere at a future time."
- i) "My attendant was not able to get health ins. and became very sick over a period of time to the point where he could not work for a couple of weeks. I helped cover the cost to get him back to being healthy, but ran into issues of finding back up people while he was out. Available workforce for backup attendants is slim."

- j) "I have to get my brother, sister-in-law, or sister to take me places and they work."
- k) "I need help with my bowel management routine and my mom works a lot of hours to help us keep our house so she cant help me and i get backed up and have accidents."
- l) "Sometimes I can't make it to where I need to be."
- m) "If they can't come, one of my parents has to take off work to be with me."
- n) "N/a, my attendants have been reliable and I've always had a back up plan in a moments notice. I also try to have an open relationship so they can feel comfortable coming to me or contacting me if they need off."
- o) "I am very independent and have not had problems with this."
- p) "No because I have four. And they are always there for me."

**Respondents were asked to explain how a personal attendant's transportation choices affected their lives.**

- a) "She has had car trouble a couple of times."
- b) "They use the family car. This can cause problems if they get in a wreck. Sometimes they don't have personal drivers insurance because they don't even have a car, but do have a license. If they don't, it falls back on my family's auto insurance and affects our rates."
- c) "Not always reliable vehicle but she always manages to get here one way or another."
- d) "Their car breaks down often and cannot afford repairs."
- e) "A friend of mine recently contributed to a new car for her so she wouldn't need to borrow other people's vehicles to come to work."
- f) "When their car breaks down, I have to get a back-up - right now, I can call my other attendant to cover but in the past, I've had to call the agency for a substitute and then wait hours before they showed up. It meant I had to miss work."
- g) "Before she was able to buy a newer car, her other one was very unreliable and kept breaking down. This meant she was either late or couldn't come at all, which meant whatever I had planned was interrupted or canceled. Basically, my life is contingent on my attendant coming."
- h) "Can possibly cause delay."
- i) "When I wasn't working and able to pay as much and he only had a few clients and his pay-rate was lower, he could afford repairs on his vehicle. Every time it broke down he would be late or could make it. Sometimes that meant not getting out of bed and off to work on time or having to miss work."
- j) "If they can't get to work, I have to call my brother, sister-in-law, or sister and they work too."
- k) "She has to leave early to catch the bus."

**Respondents were asked to share their experiences and insights about how not receiving attendant services would affect their lives.**

- a) "My only option would be a nursing home."



- b) "It would break our family apart."
- c) "My parents would not be able to work and provide for my needs."
- d) "Not be able to get out of bed, work, have a life. I'd be in a nursing home most likely."
- e) "Continue to suffer in silence and remain isolated."
- f) "Have to move back with Mom."
- g) "I would be completely dependent on my 70-year-old mother."
- h) "I would die; I can't get my own water or get out of bed. My nearest family is over 1000 miles away and unwilling/unable to take care of me."
- i) "I would try to keep my son in my home with me as long as my physical and mental health would allow. I would have to quit my job."
- j) "I don't know I need someone with me always. I'm quadriplegic."
- k) "I would have to go live in a nursing home or state hospital. I can't care for my self."
- l) "I don't know. Well, I do know I wouldn't be able to stay in my home."
- m) "I would have to live in a nursing home."
- n) "I could survive, but it would make life a lot harder and more stressful. I would probably get sick even more frequently than I do now. Like I said before, I would have to depend on friends and family. That would put a strain on my relationships with them because they have their own lives and can't stop everything to take care of me, but there's no way I would go into a nursing home or any other long-term facility."
- o) "Freak out. Call my aging mom for help. Talk to neighbors and barter for exchange of services even though just temporary till people avoided me cause they know I need help. Pay more than I can for luxury services out in the community - personal shoppers, hair shampooers/stylists, laundresses, and maids. Ask strangers walking by to help with opening medicine bottles, get trash out the house and into a dumpster, Call to order a pizza just to get a pizza delivery guy over to open up a jar or bottle. Use schwans home delivery service so they walk the food into the freezer for me. Eat a lot of frozen entrees. Start sleeping on top of my bed in a sleeping bag so sheets don't have to be changed. Join church social groups so I can eat at potlucks, just like college days! Drive really really far distances to find full service gas stations to not only check tires and fill gas tank but again, someone to ask for help with little things when they come to the window. Get rid of messy visitors - little grandkids and people's visiting pets. No messes! Stop using heavy dishes, heavy food items and pans - paper plates for no washing and stop cooking real food - can't deal with the problems and issues. Eat lots of sandwiches. Take birdbaths. Avoid heat and sweating! Stop being around people and become isolated to avoid embarrassment."
- p) "I would probably be in a nursing home."
- q) "Live in a facility certified to care for individuals on ventilators."
- r) "Rely on friends/family."
- s) "My cleaning would not get done and I would only have pre-cooked meals."

- t) "To be honest I would not have been able to graduate from college with a degree in business, find and retain a job at a senior level within the group that pays me enough to cover my families expenses, cover my attendant services, purchase a home, pay my taxes, live my life in the community of my choice not a nursing home, serve on a state board through an appointment by Gov. Perry, and serve on multiple other non-profit boards without those few hours of attendant care each morning. Without them my only choice would be a nursing home at great expense to the state of Texas."
- u) "Parents would never be able to leave home at the same time for certain events."
- v) "I would have to live in a group home or nursing home."
- w) "Struggle to do this all by myself and maybe hurt myself because things could fall on me."
- x) "I would die."

**Respondents were asked to list alternatives to personal attendant services that they have used in the past.**

- a) "Family."
- b) "When our daughter's grand parents where younger, they used to watch our children. Now Grand parents are 75-80+ and cannot care for our daughter, she is to rough and aggressive."
- c) "School but my parents pulled me out due to lack of appropriate care. They wouldn't feed me enough, they left me in wet diapers and my skin would break down. They would allow me to get hurt in other ways too."
- d) "Unpaid family support and self-pay."
- e) "Hiring people on my own and going broke."
- f) "Mom."
- g) "My mother."
- h) "On rare occasions, extended family members would help out, but it was more like respite. Our teenage son, before he went off to college, would sometimes provide respite."
- i) "Family."
- j) "Family, private people paid by my family, friends, neighbors, church helpers, babysitters."
- k) "Lived with parents but they were elderly and eventually could not provide the care I needed."
- l) "Family, strangers, maid service with lots of extras added onto services, fitness facilities for easy accessible showers, healthy food and hair services. Anyone that works at a drive through window - pharmacists, fast food workers etc. stopping living in a clean environment with a clean body, clean clothes, cupboards with shopping done and meals on the table. Going broke paying for services hanging around people I don't want to hang around to get stuff done. Scarring off friends. Putting up with people who think they are in charge of me or hint at abuse so that I get to have a necessity taken care of. Accepting a child's status or a social

dependence status of "thank you" constantly. No equality in relationship at that point. No independence. Buying beer for others just to get groceries brought in."

- m) "I have had attended services since I left the hospital. In between attendants, friends, family and nurses have helped cover the time to take care of me."
- n) "Friends; family; roommates."
- o) "Friends, family."
- p) "Family and friends but it never last that long."
- q) "Living with my parents. My Dad dies and my Mom is in a nursing home for Alzheimer's."
- r) "My parents and grandparents."
- s) "Just PAS. All of my family lives in another state, and my friends work."

**Respondents were asked to offer any suggestions that they may have for addressing any of the problem areas that they cited while answering the surveys.**

- a) "I am very concerned about loosing my MDCP attendant services. Every year when they come to evaluate whether or not we qualify we loose sleep over it. My husband and I have discussed it several times. We are not sure how we would be able to cope with loosing these benefits. It would be a disaster."
- b) "I think all waiver services should have a similar base pay that is a living wage for PCA services. I think PCAs should have opportunity for benefits not only health care but retirement etc."
- c) "Provide in our budgets for training of the personal care attendant and a higher wage to attract more desirable attendants and offer a health plan option to help attract people and retain people."
- d) "The attendants need better pay and more benefits for them to stay. Treat the job as a career where you can go some were and have better future."
- e) "My other attendants need to be paid more... \$12 or more so they will accept more responsibility. My primary helper is exhausted and feels trapped after taking care of me 24/7 for 22 years."
- f) "It would be easier to find and retain good attendant care providers if the pay was better and if we could offer healthcare. There should be one waiver instead of the many. The waiver could offer all services with each individual qualifying for any services they need. This would streamline the paperwork and make things simpler. It would probably save the state money also. People should not have to be on a wait list for 8-10 years before they get services."
- g) "I think raising the pay for attendants is vital. It's a shame when flipping burgers garners higher wages than caring for another human being. Being an attendant is a very important job and yet it is still seen as unskilled, unimportant job. Without attendant care, I would not have been able to work for as long as I did. I would most likely have to live in a nursing

home. That is not an option for me. If it ever came to that, I'd rather be dead."

- h) "I've been receiving attendant services for 22 years, but only have had 3 attendants who stayed with me for 5 years or more. One of them left simply b/c she couldn't financially take care of herself and her 3 kids. Some stayed for between 6 mos. to 1 yr. And, believe it or not, several went through orientation and never come back or come back only for a day or two, then disappeared w/o a warning. The worst one ran out of the house screaming "I can't do this!" and left me sitting in the bathtub on her first day. I have no idea what I would have done if my roommate wasn't home at the time."
- i) "If more apartments had accessible shower rooms with their workout rooms. If more apartments offered a small cafeteria for the residents - if more apartments -added on trash pick up or laundry services - not just assisted living, not segregated places - just add on amenities - it would equalize and help so many maintain independence even while losing abilities and be able to stay in place."
- j) "Attendants' should be paid a much better wage and include benefits. Those of us that require attendant services not only depend on them for day-to-day care but our lives can depend on them being there. I have lost many attendants, very good attendants that I would've liked to have kept for a long time, because they simply had to find a job that paid a wage they could live on. Attendants are special people. They want to dedicate their lives to helping others and many would do it without pay if they could but everybody needs a paycheck, a paycheck they can live on. They don't need to be worrying about how much money they make, they only want to concentrate on helping someone else that can't help themselves and needs them. When an attendant leave's it disrupts our lives. We live in our community to be part of our community, not just to lay in bed and hide away in our homes. We need attendants that feel this isn't just a job but a career. When you find the right match, we can be a part of our community with the ability to make plans and not only participate but to be counted on. It's disheartening to, time and time again, make that call to someone and let them know that you're not going to be able to be there, again."
- k) "I require 24/7 attendant care because I am ventilator dependent. This IS available in other states but not in Texas. Therefore, I'm forced to give a housemate free room and board in exchange for my overnight care."
- l) "Higher wages would lead to larger pool of qualified prospects."
- m) "The KEY is to ensure a higher rate of pay and a minimum base wage of at least \$10 an hour for all attendants out there so as to draw in a more qualified work staff across the state and to continue to focus on ways to improve retention of our current work force."
- n) "If my mom manages attendants are paid \$9 per hour if an agency manages they are paid 7.50.....they need to be paid equally so my mom

does not have to work so hard even after her job to keep me safe.... they need to paid more because they do a lot and keep me safe."

- o) "An incremental increase in services would not mean much, but a major increase would change everything. Professional service needs a professional wage for quality care. In my case, I had someone working for me that had more flexible time, but I am concerned that a more structured system would limit my independence."
- p) "Before I had CDS, I had attendant services through an agency. CDS is much better because I have more control of my attendant—I can hire/fire my own workers, I approve the timesheets before they're turned in, there's no chance that she'll be reassigned w/o warning, I have say in how my she's paid, hours are flexible as long as we're respectful of each other's schedule, and we can go out in the community."

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