|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |
| **Life Area** | **Barrier** | **Input Source/Public Hearing Location:**  **SILC IL 2022/2023 Community Needs Assessment Survey Question #1: What Barriers Have You Experienced?** | **Public Hearing Date:** |
| Accessibility | * The simple task of being able to enter all of my doctors offices by myself on a scooter. No electric door openers, and i severely injured myself recently trying to do so. Why in the heck is this an ADA requirement No ramp to get out of the house barrier free entrance's. * Downtown Monroe Mi is not handicap accessible. Also , when I lived there they gave me a ticket for parking in my own driveway the only place I could get my ramp out. There is also nothing for us folks in wheelchairs to do here. * 1. No public restroom's that include an adult changing table and a ceiling lift system (“Changing Places” all access restrooms).   2. Lack of wheelchair accessible public transportation. 3. Low pay for home health aids makes it impossible to hire and keep the support people needed  4.Public opinion and discrimination against people with disabilities 5. General lack of accessibility for wheelchair users   * having access to better services in the community * Access barriers are everywhere. * Having a wheelchair entrance to where I live. * Physical Barriers to where I cannot access a business without embarrassing manual help by associates or others. Very tight quarters in restrooms and parking lots. * LACK OF FREE SNOW REMOVAL AND MY STEP BROKE INTO THIS WEEK AND I CAN'T FIND ANY HELP. I AM A DISABLED SENIOR CITIZEN I HAVE LIVED IN MY HOME FOR OVER 36 YEARS. * Transportation, employment, and financial, equal opportunity for Medical services in the communities. * Lack of transportation, lack of affordable housing, lack of independent living supports, peer support * There are not enough sidewalks or crosswalks in Fort Gratiot, MI. It is dangerous for me to walk to nearby stores and restaurants. * The barriers I am currently experiencing involved but are not limited to the following: not enough resources in the community that would allow me to modify my home at a reasonable cost that would allow me to Remain residing safely in my home. * The ability to use my front door due to the lack of a handrail to assist with the steps. Frequent Ice and snow at the back/garage entrance, which keeps me from leaving the house or collecting my mail most of the winter * The rebirth of in-person meetings has caused me some problems with crowds and noises. * Transportation and accessible side walks * Resources to build ramps. * We moved to Michigan about 6 months ago and we are still not sure what services are available here. * I have been nothing but treated unfairly and without my wishes I would like to Explore. * Access to legal advocacy I’m seeking help in regards to my home. I’m in fear of losing my home. Upon review of my title work on file at the Berrien County Register office I became aware of several fraudulent titles. The grand total is over $500k. No one in their right mind would extend a legal mortgage to me: 1. Property value is not even $200k 2. I’m permanently disabled with out any cash infusion on the horizon. 3. My husband died so I’m with out a second source of income to pay down loan. 4. My current housing circumstances have created an very tenuous environment that threatens my health. 5. I’m financially and physically unable to advocate for myself. I have approached this matter from numerous directions. I stuttered which impacts my communication skills. I have tremors causing access to computers almost funny. I have three areas found on my brain making it difficult to recall, remember, and endure constant migraines. 6. I’m mocked on a regular basis if I need to explain why I can’t just do it myself. I’m beg you upon considering my request that if not in your area to refer my request to an area more appropriate. * There are still accessibility issues around the state. One of them is wheelchair van parking. There are often only one or two wheelchair van accessible parking spaces at * barriers that impact daily living are trying to get the support services I want to have * This is for my son who has survived a cancerous brain tumor. It is really hard to find and understand what services are available to him. Local colleges disabilities centers are a joke. A waste of time. * Many. I am unable to walk well even when using my walker to get from place to place. In my home I have small doorways that make it difficult to go from room to room. Many places I go have steps or stairs, although some have added wheelchair ramps to make them more handicap accessible. Even the ramps are difficult at times though because of the extra distance I must walk to access the buildings. Some stores and other public buildings have narrow aisles, which are difficult for those of us who are either larger (especially while accomidating a walker or other such necessity) or have difficulty dealing with small spaces for other reasons. During the summer, I would love to go swimming, but all public access to any nearby swimming areas in the lakes or rivers is impossible for me to use. The roads I used to drive to access a couple of these swimming areas are now gated by Consumers power and not accessible by vehicle. Other areas that are open for access have either steps, steep hills, or long walks to get anywhere near the water. There are some areas which are handicap accessible for fishing, but not where I can actually get into the water. My doctor has told me that one of the best exercises for me would be swimming, but even though I am completely surrounded by water, there is no place I can swim without paying to go to a nearby pool. Although there is a limited amount of curbside shopping available, it often isn't worth the charge for curbside if I'm only buying one or two items. I usually do without until I have a list worth making the trip to walmart (an hour away) to pick up my groceries when I'm going to another appointment in that area. After I return, I have to have a helper to carry the groceries in and put them away for me. * Things and places that aren’t really accessable. Bathrooms are a big one for me. * Lack of physical accessibility /transportation * Access to accessible Documents |  |  |
| Assistive Technology | * I work at disability network. I'm also blind. And I really see a lack of services for the blind and low vision community particularly in their local communities. I have experienced that myself as well with clients that I'm working with. In particular there is a lack of funding that is not related directly to employment. It is my understanding as well that the funding for the older adult blind population which is a significant portion of our population is very low. So there is really a lack of services for that population to receive training as well as adaptive technology in their homes and communities of their choice. Instead consumers are expected to travel to Kalamazoo or if they want in-home services those services are few and far between. * Lack of public funding for technology * Affordable technology, transportation, microwaves * Being able to physically reach things that are placed on a high shelf * Using a cell phone. I cannot use a smart phone and need a phone that is voice activated and not a smart phone. The phone companies are not looking at the disabled and elderly. * Unable to afford hearing aids, income just over the line [use transcribe phone] Without the phone I cannot hold basic conversations. The hearing aids are @$2,000 and word recognition is worsening. |  |  |
| Education | * Only 3rd grade literacy is being taught in special ed programs. * No independent living facilities available with resources for those with intellectual disabilities. * Confusing jumble of services, or a lack of services, for just out of high school. |  |  |
| Employment | * Employment discrimination and no policy enforcement with EEOC Michigan at will employment is the biggest barrier. * No inclusive activities, no education after I aged out, hard to get adult care, hard to find workers, and Workers needing more pay * Equitable employment opportunities are lacking. * My ability to work and make enough money to get my license back. I want to work and be a contributing member of society. * Almost no programs or support in finding jobs, job coaching, or socializing. * Limited jobs. * Transportation, employment, and financial, equal opportunity for Medical services in the communities. * Daily functions can't shower with landlord won't fix plumbing over ten years. No social security or jobs or MRS to cooperate in order to pay bills. Poverty. Bullies and worse always get away with destroying victims lives they target and rapist cops let them get away with it. No viable transportation for: laundry, post office, grocery, Dr appts, free food box days and free meals and dhhs soc sec other appts. No one helps with chores or supportiveness or kndness, or going out in cruel inhumane heartless inconsiderate selfish public. * Insufficient support in workplace for autistic employees. Lack of knowledge of how to implement accommodations for autistic employees. * I've been to vocational rehab twice with no results. I can work I have in the past I just need help and reasonable accommodations |  |  |
| Health Care | * home care and transportation * The lack of consistent skilled CLS providers. * Direct Care Worker shortage * Low pay through Medicaid habilitation waivers making it impossible to hire and retain caregivers to assist with community and work supports * Lack of reliable trained staff. * Finding a healthcare provider that can accommodate deaf patients. * Affordable/accessible housing, transportation, lack of qualified Direct Support Care workers, Loneliness. * Lack of respite providers, lack of home help providers, lack of day centers for disabled adults that support individuals that need support with all Activities of Daily Living (feeding, transferring, toileting, administration of medication) * The need for a respite care would surely help * Lack of direct care staff * Caregivers not available * Getting 24 hour a day coverage in my home. We need to grow caregivers. Make it into a respectable profession * Not eligible for in home services due to age (to young at 46) but need in home care. * One of the biggest barriers is access to adequate healthcare. And access to a healthcare advocate. I'm left to manage my own healthcare. Which basically means that I don't really have proper healthcare. * Memory. * I have a disability due to building a family and acquired it from a Hospital's lack of care and failure to treat my pregnancy as high-risk, although they claimed they were a High-Risk Pregnancy Specialist I didn't receive the basic care outlined in the ADA's Standard of Care for Maternal Medical care. As a result, I acquired panhypopituitarism and it took 10 years before I went to a teaching Hospital just to see if they would know what I was suffering from. They diagnosed me the same day as suffering from irreversible pan hypothyroidism so advanced from a neglected hemorrhage caused by lack of adequate standard of care as dictated by the AMAO while giving birth, commonly known as Sheehan's Syndrome. They lied on the autopsy of my twins and gave a false reason as to why they came too early even though I had begged for a cervical stitch that my following perinatologist begged them to place to prevent my loss and subsequent death four hours later of my twin sons who were, at 22 weeks, born alive but too early to attempt to save them. Now I have a lifelong incurable disease that will end at my earlier than natural demise. After having had the twins, I was able to finally conceive with the aid of donor egg from my fertility clinic, and I had a son, whom we later found out acquired a genetic disability from the fertility clinic's donor pool. After giving up my career to stay at home to care for my son to try and give him the best shot at reaching the highest goals despite his genetic disability, my husband of 23 years out of the blue tried to kill me through strangulation and the city decided to press charges of two counts of DV, one a Felony, mine, and one misdemeanor for doing it in full view of my son. He pled guilty to the Felony on a deal as his work is funded through the government. The Judge, nevertheless, was harsh - he gave me full custody until his probation was over, with no visitation or challenge of custody until he fulfilled his probation. However, unbeknownst to that judge, he went behind his back and filed for custody three weeks later, in family court with a Judge who claimed 'she could find no criminal record on my husband on file, so she wasn't going to use it as one of the factors when determining the best interest of the child, then switched my full custody decree to my husband, my son and mines abuser. She then dragged the proceedings out for a year and awarded him full custody the day his probation was over, claiming my disability prevented me from being a good parent (even though I had had it longer than my son has been alive. I have no quality of life without my child, and I lost the last living member of my family, my father, who died in the middle of the custody trial. I still don't understand how that could have happened that way. My son, who was really doing well in public school before this happened, has been sent to a different school for less functioning children as he refused to speak after the events and winding up with his abuser after witnessing it. He has regressed at least six years in cognitive and processing day to day life since he was taken from me. * I live alone and I can't keep up on my doctor’s appointments, medicines, and refills, cleaning my house and outside maintenance and home repairs. I have so many health issues it is crazy, and I can't find anyone to help with this stuff. If I had help, I could live life again but if I am required to continue doing it all I am just going to hang it up and die. Every time I go to a doctor, I get referred to 3 others and each is a 3 month wait. Nothing ever gets accomplished. Just scheduling my appointments, keeping my medicines coming and following up on all the unreturned medicals is at least 10-20 hours every week. Man, I am sick! I can't do that and go to all the appointments too. * Health insurance barriers. * Not finding full-time or regular homecare person for days and afternoons for bathing, changing, feeding, cleaning. * I need 24 hour support. I get confused easily and also need reminders to do important tasks. I need help for all my daily self care and basic needs. I cannot drive myself nor can I use public transportation alone. I am minimally verbal so I need a trusted caregiver to help me when I’m out in the community. * Lack of direct care staff * Schizophrenia prevents me from getting a job. I cannot drive. Also ,it would affect my disability status. * Daily functions, can't shower with landlord won't fix plumbing over ten years. No social security or jobs or MRS to cooperate in order to pay bills. Poverty. Bullies and worse always get away with destroying victims lives they target and rapist cops let them get away with it. No viable transportation for: laundry, post office, grocery, Dr appts, free food box days and free meals and dhhs soc sec other appts. No one helps with chores or supportiveness or kndness, or going out in cruel inhumane heartless inconsiderate selfish public. * mental disability * Inability to find and keep quality staff. * Lack of staff and affordable housing. * How long it takes to get ssi or ssdi. Lack of transportation. Being made aware of services (or lack of). Awareness of cognitive disabilities needing additional services in community when they are not as obvious as physical * lack of housing. expectation that will always live with parents. bad or no public transportation. lack of 24 hour care. * barriers I'm experiencing right now to live indepently are people not being understanding of my services and why I get the home care help I need it's been a issue since I've lived in my community * Full time staff * I have a hard time walking and bending .I'm always in pain .I forger things and can't hold a conversation driving painfully walking the yard I'd very pinfull * Lack of Direct Care Workers * Not enough CLS hours. The expectation that family will fill in the gaps. Lack of qualified caregivers, low compensation. * As an advocate for person with disabilites, there are some Community Mental Health agencies not helping people with disabilities. They have deliberately turned away adults with high functioning autism because they can perform daily living tasks. Ridiculous * Illness that makes it difficult to function or utilize services, living alone with no supports system, leading to loneliness and depression, costly private home care and insufficient “senior services” with long wait lists. While Grand Traverse County proudly boasts of how many seniors they serve they don’t tell you about long long wait lists, how many never get served, and inadequate, limited services—like 1-4 hours a week of respite, housekeeping, personal care, and companionship. * i cannot walk, bend, sit or stand for long periods due to chronic pain in my spine. i also have debilitating PTSD due to multiple rapes, psychosis, a phobia of the internet and multiple other mental illnesses that make it hard to access community programs without help. * I have a fragrance-reactive disability. Every business of 'public accommodation' uses fragranced cleaning products and/or essential oils in its building management, INCLUDING healthcare. Approximately 30% of Americans have some degree of fragrance reaction ,including to the extent that it is a disability for MANY. We are disabled people who are everywhere but allowed to be nowhere in society. The presence of fragrances/essential oils makes every grocery store, every building, every government agency, AND all healthcare inaccessible. That one thing, the use of fragrances/essential oils in building management, has completely ruined my life and my health. My family can do the errands and the grocery shopping for me. Not ideal to not have that independence, but at least that can be adjusted for on my end. But my family CANNOT do my healthcare for me. I haven't had a neurologist for my chronic neurologic condition for 11 years as a result. I have no access to any healthcare since 2012, including no health maintenance. I have had no dental care for six years and have active dental infections that are untreated because I am refused treatment when I ask for the dental clinics to remove the fragrance barrier so that I can have care. I'm told if I want care, I have to self-accommodate by wearing a mask, which is impossible when what I need is dentalcare. I cannot sustain my life when I have acute healthcare needs that are being refused care. All businesses, especially HEALTHCARE, must be accessible at baseline to ALL disabilities, even the 'unpopular' ones. Fragrance barriers are physical barriers that are no different to me than steps are to a wheelchair user. |  |  |
| Housing | * Lack of aging in place assistance such as inaccessibility of lower cost senior housing, lack of property tax abatements for home or reduced cost services * Lack of housing that someone on disability can afford. * No facilities designed to provide safety for a rare condition (Prader-Willi syndrome) requires food security and additionally due to the least restrictive environment clause of Medicaid people with this condition cannot live with those who do not require food security. Because it is rare there usually rent any placements close to home town—most just in metropolitan areas. Not even many options in the entire state. * Not enough low income apts. * Affordable housing that is accessible/barrier free/universal design. * Lack of safe, affordable, accessible housing. * Low-income, subsisting on SSI only. It is difficult to get a housing voucher, but even more difficult, and almost impossible to find, subsidized housing to use with the voucher. Also, mass transportation is sparse and expensive. * Affordable housing * There is not enough housing or staff! The housing situation is at a crisis level. My son, autistic/dev delayed has been warehoused in a psychiatric hospital for 9 months because there are not enough Specialized Residential facilities. There are not enough supported living arrangement openings or staff for them. The conditions in the hospital that my son is trapped in are worse than being incarcerated. Even in a jail, the inmates can go outside. My son is lucky if he goes outside for a few minutes - twice a week! Last week in the dining area a patient punched my son several times in the face, for no reason. My son now eats his meals in his bedroom. There are a number of people like my son trapped in this unforgivable situation. * My disabled sons rent kept getting h to high. * Mobility is hard and there is not enough disabled housing in Michigan. * stairs and elevators that are broken. * Affordable/accessible housing, transportation, lack of qualified Direct Support Care workers, Loneliness. * Housing cost * I don't live independently! * Not enough options for independent living at my level of disability. Need more choices at different disability levels. * Low income housing programs * Not enough money & not enough housing available. * Lack of housing for the higher need/severely cognitively impaired population & non-existing day programs for non-vocational I/DD recipients. * More public transportation, more affordable and accessible housing. * Affordable accessible housing. * We are now just entering this experience of finding living outside of the home. The barriers that I see are access to what's available. * I am the parent of a young adult with a disability, and I would tell you this is not going to come as a surprise to you. It's just we are working really hard on getting him into an apartment and we just cannot find the staff. And that's the single biggest barrier we have right now. * Access to apartments, etc. in “walkable” cities as transportation is limited. Also, finding a good match for roommates. * Avenue to meet other young adults with disabilities Possible income supplement along with my wages so I could afford housing. * Lack of transportation, lack of affordable housing, lack of independent living supports, peer support * The high cost of rent and waiting list * The barriers I am currently experiencing involved but are not limited to the following: not enough resources in the community that would allow me to modify my home at a reasonable cost that would allow me to Remain residing safely in my home. * Transportation is a huge factor. Also finding affordable, accessible housing * rents to high and i got approved for the home i jst movedin i was homless and domestically abused to the point i can hardly have a life our home now thank God he got us a place i washomless and beaten and traumatized and he thretened to rape my son and i thnk something happend im trying to involve the police hes personality * accessible and affordable housing * Access to safe, affordable housing. Especially barrier free/ wheelchair accessible housing * Affordable housing * Sunday city bus schedule only runs once an hour. This is insufficient for getting to and from work. There is a shortage of affordable housing. * Lack of supportive housing options for persons with mild cognitive impairment, too “high functioning”. * Lack of staff and affordable housing. * There isn't any housing * I live in HUD bldg in one of two handicap accessible apts. Neither the bath rm or kitchen are fully useful. There is tub not a shower. The kitchen cubbards are so low none of the general appliances will fit under them without being a fire hazzard. Front entrance requires going thru 2 sets of double doors that have glass in them. 2 optional entrances does have a lower push bar accessible from sitting position. None of the entrances have automatic doors. The trash containers are outside with only top of container lids. They are not at a level where u can open from sitting position. I the winter there is lot of ice where u have to stand to get trash in containers. Only other option is to put in hallway/apt entrance door 1x per week which is then disposed of by maintenance. * lack of housing. expectation that will always live with parents. bad or no public transportation. lack of 24 hour care. * This summer we tried a residential home for my son, the home was unable to support the social and activity level he was accustomed to at home. We believe this was due to staffing and limited training of staff. He is now back at home and he is happy, while we have no support for respite. * Lack of ease in finding resources and places that are based on income not in an apartment community. * Transportation and housing * Financial. I am on a limited income due to disability and can’t afford rentals or qualify for a small home loan because my debt to income ratio is too high. * People with no disabilities living in apartments. * Housing * Homeless since June 2022 * Affordable housing * Unscrupulous landlords towards disabled, elder long term tenants. * Lack of accessible and affordable housing. Not just in apartments, but in rental properties and homes. * Accessible housing * living in a rural community, resources are harder to find and knowing who to reach out to is frustrating. Transportation is hard to come by if you can't drive or don't have a vehicle. Housing options are limited. |  |  |
| Other Supports | * The issue of least restrictive enforcement makes living in a residential setting very difficult for people with PWS as food is not restricted for others so unsafe for people with PWS. * No advocate, no transportation, ageist (biased) doctors, lower fixed income (partner died), no homecare, no (legal, medical) voice, no garbage or recycling pickup, no social life, overmedicated and misdiagnosed, no tech skills * Completely non-functional Center for Independent Living. * No day programs for people that require a high level of assistance with activities of daily living. * It's expensive to pay for the things I can no longer do. * I need help with daily chores but can't afford to pay for it. * So so so many, legal, home support, executive function, abuse support for myself, abuse support for my children, I'm disabled and constantly in survival mode everywhere but can't get help, victims rights supports, administrative, system failures like dhs, my children are disabled as well as me and sexual abuse AND abuse from the other parent causes chaos because I can't get support, loss of child support causing massive financial issues, help with civil   lawsuits   * My daughter lives in an assisted living facility that has air conditioning in only common areas not the individual rooms. They can have an individual unit IF they rent one from the facility ONLY at a cost of over $100 per season. Also the facility is beginning to double up in the rooms making privacy an issue. There is one staff member per 8 hour shift for now 18 residents. before they started doubling up it was 15. Staffing is a problem. * No affordable help with outside chores like yard maintenance and snow removal * Money * I have mental health issues and also unfortunately substance abuse in a history plus made a mistake called felony in 1994 I’m 58 and it hurts me to this vary day please 🙏 served my time and can't be expunged not a sexual crime not murder crime of property arsenal but dwelling house occupied I think penal code can never be exposed I think it can be set aside and also attempted murder May show up I spent several hours in jail overnight from somebody attacking me and they got hurt haven't been in jewelry / handcuffs and 24 25 years of one for that God it would be come on one felony 19 days in jail my whole entire life until then no saint but society does not forgive. * No inclusive activities, no education after I aged out, hard to get adult care, hard to find workers, and Workers needing more pay * 1. No public restroom's that include an adult changing table and a ceiling lift system (“Changing Places” all access restrooms).   2. Lack of wheelchair accessible public transportation. 3. Low pay for home health aids makes it impossible to hire and keep the support people needed  4.Public opinion and discrimination against people with disabilities 5. General lack of accessibility for wheelchair users   * Not enough to do. My son is high functioning but language impaired. * No help after graduation at 26 * There is little help finding people to plow snow, mow lawns, fix serious breakdowns in emergency situations (furnace, electrical, etc.) * Personally none * Food Prep is the biggest. We have no meals on wheels in our area for disabled people. My also physically disabled partner & I have no better quality of life than my senior mother (she actually gets out more), but gets home delivered meals. We are already food insecure, but never have a hot meal. We survive on things like cheese/crackers, sandwiches, cold cereal &yogurt. The other meal prep options (local & delivery) are out of our reach do to cost. Even on days we can get out, there's no options for disabled people to gather/get a hot meal/do activities, like the senior sites, also available. I think their may be more options for the cognitively-impaired, but we are non-senior physically disabled (both receiving SSDA) & have found almost no resources for us. * Guardian response. There is not much around for those that are fairly independent but still need guidance * Mailbox to hang on door would make it easy to access or cloth mailbox easy to retrieve through holes in ornamental storm door. * Few to no social opportunities for young adults for social events or job coaching. * Lack of support from the CMH to attend activities in the community. Also, activities that are planned/organized by CILs are considered to be in the community, although they are disability specific. * People living on there own right now in the real word * Some of you may know we support 12 counties in central Michigan and through a enter for independent living here and we hear frequently are in regard to public transportation, Saginaw County is the largest in the area and only serves city of Saginaw. So we have disparities in community resources because of lack of transportation. One of the other things we would like to see is representation of individuals with disabilities in leadership or decision-making positions, even at the local level. That's been a huge concern for folks. * I work at disability network. I'm also blind. And I really see a lack of services for the blind and low vision community particularly in their local communities. I have experienced that myself as well with clients that I'm working with. In particular there is a lack of funding that is not related directly to employment. It is my understanding as well that the funding for the older adult blind population which is a significant portion of our population is very low. So there is really a lack of services for that population to receive training as well as adaptive technology in their homes and communities of their choice. Instead consumers are expected to travel to Kalamazoo or if they want in-home services those services are few and far between. * One of the biggest obstacles for my family is that our son is so severely cognitively impaired and so incontinent that there really is a huge barrier for how he can be in the community and right now he is still in school. But once he graduates at age 26, what I'm finding is community mental health of Ottawa county is depending on me hiring direct care support to come into the home or take him into the community. There are some programs for those that can live or that can speak or maybe have less cognitive impairment. There is a few programs for them. But what I'm finding is my son is really being discriminated on. That he doesn't meet criteria and therefore there are no day programs. And there is no place that he can meet other peers in Ottawa county. * Access to services from community mental health and approval of appropriate budget to meet the needs. * The lack of caregivers. * Affordable technology, transportation, microwaves * Shortage of DCW, limiting my kids ability to go out in the community. * Discrimination among peers and other individuals taking advantage of the resources available to them. There are many people taking advantage of programs and incentives or finding a loop in the system that's actually making it more difficult for people that need these very barriers removed not only for themselves to become independent but for their children. I have teenage children, 17 and 14 to be exact. It's not a matter of education. Although I support education and knowledge I just feel as if the system has been abused and it's easy for peers young and old to manipulate a group of people if they have the right influence and incentive to do so. What about the individuals that aren't able or have the right groups to compete or fight for their lives or children's best interest? Our children are our future and my ability to live independently in my community comes down to discrimination among a wide range of people in more than one rural community. * An individual not seeing my disability. * General support group. * Multiple disabilities - unable to live alone. * no social gatherings. * The cost, knowing how to pay bills, knowing how to use public transportation, the ability to cook more meals without help, etc * Money * rents to high and i got approved for the home i jst moved in i was homless and domestically abused to the point i can hardly have a life our home now thank God he got us a place i was homless and beaten and traumatized and he thretened to rape my son and i thnk something happend im trying to involve the police hes personality * Gathering is more complicated, but needed. * Temporary income while waiting for ssdi approval. How are people supposed to pay bills for a year with no income? * Affordability * How long it takes to get ssi or ssdi. Lack of transportation. Being made aware of services (or lack of). Awareness of cognitive disabilities needing additional services in community when they are not as obvious as physical * I live independently * Poor memory, impulsivity that mismanages priorities, difficulty applying today's learnings broadly and using information in multiple settings, not able to cook, need lists for everything but can't make them alone. * Watching TV and Playing Video Games. * None * Lack of community opportunities |  |  |
| Recreation | * Shortage of weekly activities. * Accessible playground even at school. |  |  |
| Relocation |  |  |  |
| Transportation | * No public transportation in my rural area and I don't drive. I'm missing many dr appts because of this. * Lack of transportation & transportation costs * No advocate, no transportation, ageist (biased) doctors, lower fixed income (partner died), no homecare, no (legal, medical) voice, no garbage or recycling pickup, no social life, overmedicated and misdiagnosed, no tech skills * Low-income, subsisting on SSI only. It is difficult to get a housing voucher, but even more difficult, and almost impossible to find, subsidized housing to use with the voucher. Also, mass transportation is sparse and expensive. * home care and transportation * Transportation. * Lack of convenient transportation to medical appointments outside of my town. * Accessible transportation in rural areas and which cross county lines which are reliable * Affordable/accessible housing, transportation, lack of qualified Direct Support Care workers, Loneliness. * 1. No public restroom's that include an adult changing table and a ceiling lift system (“Changing Places” all access restrooms).   2. Lack of wheelchair accessible public transportation. 3. Low pay for home health aids makes it impossible to hire and keep the support people needed  4.Public opinion and discrimination against people with disabilities 5. General lack of accessibility for wheelchair users   * transportation to appointments * No available programs to meet more involved needs, wheelchair accessible transportation, NO accessible transportation in the evenings and on weekends. Currently, no transport is available for activities or events after 2 pm here (Saline). Lack of staffing for CLS Assist. * More public transportation, more affordable and accessible housing. * Public transportation is good where it exists, but is very limited geographically. * Not having access to affordable and reliable transit for seniors and disabled * Lack of transportation * Affordable technology, transportation, microwaves * Taxi fare too expensive; but is very limited and all too often cannot ride due to one of my disabilities, unable to access home help via county or the state; only able to get 2 of my vital supports met out of 8 here. * Access to apartments, etc. in “walkable” cities as transportation is limited. Also, finding a good match for roommates. * Transportation, employment, and financial, equal opportunity for Medical services in the communities. * Lack of transportation, lack of affordable housing, lack of independent living supports, peer support * The cost, knowing how to pay bills, knowing how to use public transportation, the ability to cook more meals without help, etc * My father lost his driver's license due to a health concern. He's still mobile and active but feels like he's held hostage at his home * Transportation is a huge factor. Also finding affordable, accessible housing * Schizophrenia prevents me from getting a job. I cannot drive. Also ,it would affect my disability status. * Daily functions, can't shower with landlord won't fix plumbing over ten years. No social security or jobs or MRS to cooperate in order to pay bills. Poverty. Bullies and worse always get away with destroying victims lives they target and rapist cops let them get away with it. No viable transportation for: laundry, post office, grocery, Dr appts, free food box days and free meals and dhhs soc sec other appts. No one helps with chores or supportiveness or kndness, or going out in cruel inhumane heartless inconsiderate selfish public. * Transportation and accessible side walks * Sunday city bus schedule only runs once an hour. This is insufficient for getting to and from work. There is a shortage of affordable housing. * How long it takes to get ssi or ssdi. Lack of transportation. Being made aware of services (or lack of). Awareness of cognitive disabilities needing additional services in community when they are not as obvious as physical * lack of housing. expectation that will always live with parents. bad or no public transportation. lack of 24 hour care. * Transportation is the biggest problem. When the special needs person lives independently, there is rarely a driver available to drive to and from work. Busses do not work late enough. Private drivers that qualify for drivers to and from work, aren't available. Can Uber and Lyft drivers qualify for reimbursement from work plans. * Transportation and housing * Transportation * No good public transportation * Lack of Door to door transportation for those who cannot drive. * Need rides to and from the grocery store that's not a transportation bus. * Transportation. My community only services the immediate jurisdiction. I would love to use the transportation services to get to my college classes. * Transportation - do not drive and don't live near a bus route. * Lack of physical accessibility /transportation * Wheelchair Accessible Transportation * living in a rural community, resources are harder to find and knowing who to reach out to is frustrating. Transportation is hard to come by if you can't drive or don't have a vehicle. Housing options are limited. * Transportation- limiting transportation so you cannot go outside city limits unless it's for medical appointments. Who can have all their needs met within the constraints of their city? When you are able to find accessible transportation that goes outside your city and maybe travels throughout your County we're still unable to cross County lines. * Transportation. Lack of public transportation. |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **Life Area** | **Barrier** | **Input Source/Public Hearing Location:**  **SILC IL 2022/2023 Community Needs Assessment Survey Question #2: What Would You Like to See Changed in Your Community?** | **Public Hearing Date:** |
| Accessibility | * A little more awareness of things that make our life difficult. Like what I said above. And restaurants I cannot access I could go on and on. * Accessibility, more accessible outings, more things to do with grandchildren, ssi updates to allow marriage more accessible pathways and sidewalks ...especially in parks and beaches (access to the water) * more access to better services * Making services available easier so parents have access to what is available * Bathrooms need to have a pull-up bar in each stall. I use a cane when shopping use electric cart. I don’t need handicap stall very far away if I could use regular stall all I need is pull-up bar. Handicap stalls are very far away. Doors at banks do not have handicap button to open. When using walker struggle to open doors very heavy. When grocery shopping glass doors instore very difficult to open and access frozen goods * More parking space that are wheelchair accessible. I'd like to attend community events, go to downtown stores, doctor offices, lawyers etc * Something that I really struggle with is just both physical and social barriers to access to just really the community as a whole. There are so many just physical places that are not physically accessible. And I shouldn't have to call, you know, a bunch of people and get the Government involved just to go shopping. And then also it seems to be that in a lot of these community spaces people with disabilities are an afterthought or, you know, people just do the bare minimum to us, but we are not considered equals in these spaces, and we are not considered for leadership positions. And really having that ability to lead and guide a lot of these decisions that are happening in our communities and our cities because we are just an afterthought. And then the accessibility is done at a bare minimum instead of looking at what's the best and what would put us at equal footing with others. * I have been concerned this season because we've had such an ice problem. Because I've seen a number of people with difficulties of any nature, whether that be someone who is a runner or someone who actually uses a device having trouble navigating through the ice and such on the sidewalks. I see this as a real problem. The sidewalks are being, you know, the little motorized vehicles are clearing the sidewalks. But that often leaves ice. And what can we do about that? * More accessible restaurants and downtowns. * Easier access to information and help to figure out how to utilize and apply for services * The awareness that it isn't just a mandatory item to check off a list for having an accessible business or not but think what makes sense to the disabled and how they access and function in these spaces. * Accessible playgrounds at schools. Accessibility at ALL metro parks. * CIL community built for those with developmental disabilities to be able to be more independent. * Written and picture communication boards for ordering at restaurants, ticket counters and training so staff know how to offer them to non verbal individuals. * Sidewalks and crosswalks installed on M-25 between Cherry Hill Dr. and Carrigan Rd. in Fort Gratiot, MI. * Continuing the hybrid attendance options for meetings and conferences. * Accessibility * Increased outreach for inclusive accessible community events. * Connection of sidewalks to b able to walk to stores. The garden group suggested I could not rent a garden plot because my walkers width might damage other gardeners plants. There are grow boxes on my apt bldgs property. However, u have to be able to walk on grass down a hill. With walker and balance problems...not accessible. I wa ted to rent srt space to be with other artists and be able to use materials not appropriate in apt. But thete are stairs. Same thing to attend monthly art evaluation group. Many places to eat have steps. * being able to go out into the community and not have others wondering who's helping me and being able to give my former CIL a chance without having problems * More events with the general public interacting with people with disabilities * Fair treatment as a member of my community regardless of disability. * Easier access to problem solving help * I would like to see communities around the state embrace accessibility for their disabled neighbors. More businesses and recreational opportunities for people with all types of disabilities. Many areas are doing a great job of this around the state. * Nicer people. A lot of old people don't speak directly to anyone with a disability. * Everyone’s basic needs being met. * Accessibility and Transportation * I want to feel more accepted as a member of my community. * I would like to see more easily available resources for those of us with handicaps. More curbside shopping without a lot of added expense would be great. A handicap access to any of the local swimming areas would be wonderful. I'd also like to see more activities available for socialization. I'm not sure, maybe this last one might be out there somewhere, but I haven't found it if there is. I know there are many of us who are basically shut-ins, barely leaving the house except for appointments. It would be nice to get out and socialize from time to time when my health permits. * More inclusion and a stronger push for accessibility in Barry County. More identify of the IL Philosophy and services throughout Barry County. * More universal design in the community * Higher pay for home help workers, to get rid of 14C wavier in the state of Michigan, and more services for students in college trying to get accommodations. * access to social workers, homes for the homeless, a liveable amount of funds for the disabled who don’t have families to protect them * All entities doing business with the public MUST operate accessibly at baseline, including fragrance-free building management. Going fragrance free is one of the easiest changes that can be made to improve baseline accessibility; it is not a burden and even saves the entities money. I want to see all entities doing business with the public operate accessibly, including being fragrance free at baseline. The only exception I would grant is when going fragrance free is antithetical to their core business operation. For example, I would never ask Bath & Body Works to be fragrance free, because their entire business is fragranced at baseline as that is the product that are selling. But that excuse cannot be used for a dental office as fragrance is not a key component of dental care. Let's face it, people with fragrance-reactive disabilities are NOT asking to enter fragrance stores. * Programs to get those more involved out into the community via transition and offering of programs that meet their needs. * Rural outreach and services through community support and cultural understanding Developing strategies. for recognizing goals of each person with a disability in rural communities related to improving their independent living. |  |  |
| Assistive Technology |  |  |  |
| Education | * More help guiding people before a person becomes an adult so they are set up for success. Anyone with parents that make a normal living have very hard time accessing resources. Once u age out of those services there is no transition assistance to help guide that transition. * Self-selected free basic & essential services and trustworthy knowledgeable advocates, cellphone & internet training, transportation * people not to assume and realize everyone is different medicine has come along way and taking care of youself does matter * increased education about mental illness and health, decreasing stigma and more peer support. * for life coaching those who struggle with friendships. * Training for direct support care providers, community awareness of disabilities. * Education and safety. We deserve a 6th grade literacy level and safety from neighbors and police officers who do not like to see us in public. * More transparency on services available in one's place. We are directed to look at the 211 United Way website which is difficult and outdated, CMH websites lack transparency to obtain these services. You get referred and referred around in circles. * Ignorance towards people from different upbringings * More resources for post-secondary education, therapists, caregivers, and staff, and maybe recreational activities for people like my daughter. * Assistance with transitioning into the community out of high school if college is not the plan. Additional transportation options. Assisting parents with knowledge of what now. * Make transportation more accessible.   Also, education concerning financing.   * I would like to see more services for those with disabilities outside of school. As individuals age, there is no help for their guardians/parents. * More leadership opportunities for youth. Collaboration with local school districts to teach IL skills and Pre-employment skills. |  |  |
| Employment | * Ability to obtain limited in home care at a reasonable price or to have insurance cover a portion of the cost. Ability to work limited hours as disease state allows and not be penalized for being a high wage earner. * More job opportunities for people with neurodiversity. * More inclusive communities, workplace support, and supportive groups. * More dependable transportation, trainers for driver's license. Better opportunities for employment, equal pay for the employment. Savings plans for the future, and equal Medical Services for the disabled in the community. * Study and get a job a cloth. * More education for employers on how to support autistic individuals. * More help for disabled former business owners. There is literally none and some of us are best suited to our own small biz. Voc rehab says they help with it but have no idea how to do so with someone on SSI, not SSDI on SSI. We have different rules and somehow no one seems able to understand them and help people like me |  |  |
| Health Care | * 100% property tax abatements for primary home of seniors over age 70 and significantly improved home healthcare services including hospice ruined by state licensing changes. * More access to mental health support for people with developmental disabilities. Our son was excluded from access to CMH services because he could not qualify for the SED waiver because although he likely would have qualified for it, he was excluded due to developmental disabilities and he was excluded for the developmental disabilities waiver because his condition is rare and not easily understood and not need more typical services like nursing or a wheelchair but has a more hidden disability that limits his independence in significant ways preventing him from living independently or from even being alone for a few minutes. We have been forced to seek psychotherapy treatment over an hour away from home because CMH is   both understaffed and tends to exclude people with rare conditions.   * CMH/PIHP’s provide the actual services they receive funding for. CMH/PIHP promote Self Directed Services with fidelity to contractual obligations and technical requirements. * Increase pay of direct care workers to a living wage * Medical services available for individuals with significant disabilities. adequate Dr.s in all communities willing to take Medicare. Timely services available….not long waiting lists/times. * Healthcare providers have a protocol in place to help protect the patient, From my experience they don't have one. * Compassion they have mental health in the shelter in Ann Arbor Michigan extension of the mental health ward and University of Michigan hospital in St Joseph hospital in Ann Arbor Ypsilanti respectfully please bring back mental health hospitals other than the ones for prisoners. * Multiple CMH’s in the west Michigan region all reporting the Lakeshore Regional Entity (LRE)needs to be seriously reviewed & separated as it once was. This reporting structure create slack of non-biased objective oversight & accountability. Recipient rights complaints are unfairly managed by the very same managing (LRE) & that creates a system by structured design with an unfair way to report complaints or ability to appeal. (Basically the Fox guarding the henhouses) * Ability to obtain limited in home care at a reasonable price or to have insurance cover a portion of the cost. Ability to work limited hours as disease state allows and not be penalized for being a high wage earner. * Mental health resources for teens living with developmental disabilities. * the ablism, complex trauma training is needed and the one size fits all approach for disabled and chronically ill needs to go. I would like to see disabled folks get a caretaker and an individualized voc rehab support person like they do in MN and MA, I would like to see a complex trauma training and treatment center here for many reasons, support services are desperately needed for those who are disabled and elderly. * I would like to see Developmental Disabilities not under Mental Health in the MDHHS. It should be its own department. MDDC is not an adequate oversight body. I would like to see more and better services for the I/DD community, more consistently applied throughout the state. * inclusion in every area for people with invisible disabilities especially; the county and state should work together with community resources to provide private rides for folks in special needs categories like sensory processing disorders and trauma disorders for example. Also, would love to have access to free or sliding fee scale regularly planned social activities; a regular home nurse visit and in-home mental health support for those who are their only caretakers. The community needs to be better educated on invisible disabilities so it can pool it’s resources from the area on aging (which needs to drop its age to at least 55), to disability network, women’s resource center, along with county and state nonprofits or agencies including DHHS should all be able to work together in an efficient way to provide much needed supports for its most vulnerable disabled population. I would love it if the local DHHS could assign me an individual caseworker that could set up a team of supports for people like me. * More dependable transportation, trainers for driver's license. Better opportunities for employment, equal pay for the employment. Savings plans for the future, and equal Medical Services for the disabled in the community. * More Homecare Agency for Seniors. * I would like to see changes within the Health insurance industry for example, the health insurance industry often will tell a person with the disability what they need and not allow the person with the disability to obtain what they themselves feel is best for them. Example: if an individual needed A mobile scooter because it is safer for them and it will also allow them to get around more independently. However, the insurance may deny their request or their need for a mobile scooter but might suggest or be willing to pay for a manual wheelchair. * Amount that is allowable to pay caregivers * More housing options; more social / recreational programs for young adults with mild cognitive impairments (maybe through the local Y center?); increased awareness of the effects of drinking alcohol while pregnant which results in FASD * Caregiver guardians getting paid to provide services when paid staff is unavailable. Quality care and training of staff. * I would like to see more awareness, screening and coordinated care for persons with brain injury. * Cauda Equina Syndrome: Neuropathy right lower portion of the body and chronic pain * Complete immobility. Need assistance ( lift) to move anywhere. * i have combined type adhd/anxiety * I was not able to complete the paperwork required to keep my disability payments and I am afraid of losing Medicaid * Access to Mental Health services and programs that help with being homeless * People knowing each other more and shifting focus from isolation to community focus. Improved infrastructure for mental health. Wellness incentives. Community classes for differently abled persons (professional coaching, public speaking, cooking, driving) * I would like to see more resources available for families with children on the spectrum, the current incidence is now 1 in 36. Trained professionals and para professionals would a big improvement. Case management for adults who have credits to gradutate but are not ready. They need help over and above. * Senior services to be actually available and affordable. But most important is affordable and high quality of life living that fosters interaction and companionship. There also needs to be financial support for caregiving by a relative who cannot earn an income with a 24/7responsibility. See comments below * More housing options, better wrap around services for those with mental health and brain injury conditions * We need legal support through our CIL. I've been talking to our CIL for four years and have made no progress toward getting me healthcare (my focus for life-sustaining reasons). The discrimination that I face for having a disability is grotesque and eugenic at its core. The only way that it will change is for the discriminating entities to have legal exposure or face monetary consequences. When I asked for help to find a lawyer, I was refused that support. I later learned that I was refused that support because the laws surrounding disability rights amount to structured begging and that there aren't really any lawyers who are even practicing in the Title III ADA realm. It is imperative that the most difficult cases like mine have full support, including legal direction. Leaving me to fend for myself is NOT a sustainable plan. * There should be college certifications for direct care workers. * There are not enough activities for adults who are cognitively impaired. Bite my tongue but some low producting folks should get subminimum wage. They do not care about the money they want to got to "work" and visit their friends like the rest of us. |  |  |
| Housing | * 100% property tax abatements for primary home of seniors over age 70 and significantly improved home healthcare services including hospice ruined by state licensing changes. * More inclusive housing and community; not segregated housing for persons with disabilities. * Housing specifically targeted to younger adults w/disabilities, that would include wrap around services within the bldg or the community. * Adding more of the above-mentioned housing and not having to wait 2 - 5 years to gt into what is already available but also in many cases substandard. * Safe, accessible, affordable housing. Build more low income housing and make transportation a priority. * Affordable housing & DHHS being accessible and having workers to help with their programs. * Require proof of citizenship before being able to purchase a property. * Housing and staff are needed immediately! The State of Michigan will be sued over this (another state was recently sued for housing disabled people in hospitals because the state failed in it's duty to provide adequate housing). * I would love to see help for disabled people to move. It’s bad enough that I’m on a second floor but I can not move boxes up the stairs by myself. * Affordable housing. I have no choice but to stay in my house because there is no independent living for disabled people. * More inclusive adaptive recreation. More community awareness of different abilities of people. Safe, accessible, affordable community housing, not group home. CMH/PIHP’s to do their job providing appropriate services in a non-toxic, non-adversarial way. * Affordable housing and transportation * More facilities for individuals with intellectual and development disabilities. Higher pay for staff Guardians able to be paid caregivers * 1.Better approach and attitude to people who are different 2. Changing Places restrooms in all public venues 3. More inclusive programming for all public venues and organizations 4. More universal design and accessibility * More affordable housing * affordable housing in a walkable downtown - I can't drive because of my medical condition * More independent living options for people who are disabled physically but are not neurological, mentally disabled. In other words, have higher cognitive abilities but just can't live completely independently without some supports. * More wait list for low income housing rather than once or twice a year * More affordable housing, more buildings with services inside of the bldg. * We need independent housing for adults with autism that provides 24/7 support that is not a group home. * There needs to be support for affordable and suitable housing for us available at a price point we can sustain * overall transportation and housing in the community and better access to those would be wonderful. * So for change within the community, I think it would be important to have housing that matches the funding that people have access to in a safe community. I work with a nonprofit that we have significant trouble trying to get housing for our community members. * I am housing an accessibility specialist for our CIL. And housing is a very difficult problem. There are resources such as 211, which I think can be very valuable generally. But it is a very large problem. And I would encourage anyone to be diligent and really advocate for themselves or short of that, find a good advocate. Because, you know, again, it takes a lot of digging to solve these problems. * I'm curious to know because it's finally only taken me three years to get my SSI. And I feel imperfectly able to be able to start living on my own independently. I'm curious to know how I'm going to be able to find, you know, an apartment or wherever I may be able to live at what price, you know, like is I don't get nothing for an income. But like 600 and some odd dollars and 300 in food stamps. * Affordable and accessible housing available in and relative to every neighborhood. * More safe, low-income housing for seniors. * More low-income housing with wheelchair friendly entrances- showers, pocket doors, doorways, electrical outlets up higher from the ground, being able to wash dishes while seated in a wheelchair. * More public transportation- further and more hours available, more affordable housing options, more independent living supports, peer support for young adults, more young adult services- not children or seniors- young adults, benefits counseling and coordination * A house or 2 specifically for FASD adults, with a good staff, inexpensive room & board. * More affordable housing a cap put on homeowners that rent. They should have a cap on how much a 1 bedroom should be compared to 3 bedroom home. Or by square footage going on that counties cost of living assessments. Not fair paying 600 for a 1 bedroom and a 2 bedroom is 550. Something needs done. My friends landlord raised her rent $200 because they could because they either Want her out or recover from drilling a well totally unfair * id like for to stop being harrasset constantly by the police because of my dissabillities please if u cant please help me talk to her id only need 2 months and id have enuff to move in my abuser and captor stold all our clothes furniture eveything but some nice places in town helped us get some things plus i havent had that low of rent ever not even while homless i had to pay to stay at ppls homes this house is light and airy beauriful private perfect for our cptsd 9893400258 ty * Increased access to section 8 vouchers (or other methods of subsidized housing) for people with disabilities. More understanding, especially in Wayne County, DWIHN, that people with disabilities should have tenancy rights and the ability to control their own front door, regardless of their physical needs or intellectual level of care. * more affordable housing for people with disabilities, not just seniors * Affordable housing is beyond needed. * More frequent weekend city bus service. More options for affordable rental apartments or condos in the city of Grand Rapids. * More housing options; more social / recreational programs for young adults with mild cognitive impairments (maybe through the local Y center?); increased awareness of the effects of drinking alcohol while pregnant which results in FASD * Affordable housing options. * More shared housing with aides. * more housing, better public transit, instructions on how to get a better services plan, why do we have to fight for getting needs met * More independent income based housing separate from apartment living. Having Autism and social anxiety isn’t great in those communities. * More public transportation or even private transportation! More affordable housing options * Add some senior housing that is cheaper, for low and mod income seniors, not just single disabled or elderly who qualify for very low income. Lots of people are just over the line. Rent is increasing too. * More low income housing so people don’t have to wait 2-8 years. * More housing assistance. Would like a designated agent or place to help review options and get into a place. * More places to submit unscrupulous landlords; with Attorney General Office, FTC complaints, changes to laws against Bullying disabled tenants * @StopBullyingCoalition.org chapter is coming to Michigan * i want to move * higher focus on housing intertwined with other resources to maintain housing * More housing options, better wrap around services for those with mental health and brain injury conditions * Extended routes and hours for pubic transit. Accessible walkways and outdoor areas. Affordable and ACCESSIBLE Housing. * trauma programs and rehoming programs for those that are homeless, and people who are living in dangerous settings. |  |  |
| Other Supports | * More free & low cost events. * I would like to have a functioning, consumer-controlled Center for Independent living focused on deinstitutionalization and other priorities set by the local disability community. * A day program for individuals with high level needs so that their family/caregiver could remain employed. Our current system forces families to quit their jobs to stay home and care for their loved ones because there is no day program for people over 26 in our community. * Volunteer organizations to help seniors/disabled folks with house and yard work, and special projects. Perhaps along the lines of Habitat for Humanity. Tax breaks to business owners who offer free/discounted services to seniors and the disabled. Informal groups of friends who spend time at least once a month to work as a group on projects for each other. * More funding for caregivers and home modifications like ceiling lifts, ramps, etc. * There needs to be a way to get help * More services in home. He needs support with mail, cleaning, cooking, keeping a calendar, finances, transportation for medical monthly, & just to get out and have fun. * In home support like wrap around services, executive function supports, supports for ssdi parents who have disabled children, legal system support, filling out things like dhs appeals etc. * Accessibility, more accessible outings, more things to do with grandchildren, ssi updates to allow marriage * Stop doubling up on occupancy. ALL residents can have air conditioning in their room. Incentives to keep employees, greater training and vetting of new hires. * More facilities for individuals with intellectual and development disabilities. Higher pay for staff Guardians able to be paid caregivers * 1.Better approach and attitude to people who are different 2. Changing Places restrooms in all public venues 3. More inclusive programming for all public venues and organizations 4. More universal design and accessibility * More home care and day center care for adults with severe disabilities so that their family members can receive much needed respite and allow for them to continue to work and be productive members of society. * Some type of skill building and day center to give him a purpose. Making soaps or candles or something that they could sell as well as gain experience. Similar to Dutton Farms in Pontiac but bigger and more accessible Also a place for exercises not just limited to Special Olympics * More help for our adult children with disabilities. * Activities for older special needs or disabled adults * Cities, townships, counties, and the state should create discounts on taxes, trash PU, utility taxes, essentials like food, internet, etc. * This community seems to be entirely white people. I would like to see more diversity. * Our community needs more services, programs, and options for living for those who have special needs, especially those who have severe needs. * Less Protesting around the country * Recognize that just because we aren't seniors or cognitively-impaired, doesn't mean we don't struggle daily & wish we were not a forgotten population. * Door to door accessible transportation - and additional funding so it doesn't have to come out of CLS budget. Extended hours/days for community events (including weekends). Adapted programming that meets the needs of those who have more involved/complex disabilities. Tired of being left behind with little or no forethought in this population withing the disability community. * More opportunities for young disabled adults for social events and job coaching. * I would like more individual access to the community by having 1;1 staff to do so, and i would also like more independence to be supported to attend /have relationships in the community. * People picking up their trash In the community right now * Living resources for people living with PWS. * Monroe County. So, I think that some of the biggest challenges that we face here locally, at least in our family's experience, is an understanding of self determination and understanding of what true community inclusion looks like. I think it's very prescriptive. I think that there's a lot of loss in translation from our policy makers and our policy implementers in Lansing to the local level. And I find that we are often asking our supports coordinators or other agency providers to do things that they have never heard of before but have been widely practiced elsewhere across the state. * Needs being met. * inclusion in every area for people with invisible disabilities especially; the county and state should work together with community resources to provide private rides for folks in special needs categories like sensory processing disorders and trauma disorders for example. Also, would love to have access to free or sliding fee scale regularly planned social activities; a regular home nurse visit and in-home mental health support for those who are their only caretakers. The community needs to be better educated on invisible disabilities so it can pool it’s resources from the area on aging (which needs to drop its age to at least 55), to disability network, women’s resource center, along with county and state nonprofits or agencies including DHHS should all be able to work together in an efficient way to provide much needed supports for its most vulnerable disabled population. I would love it if the local DHHS could assign me an individual caseworker that could set up a team of supports for people like me. * Discrimination and groups of individuals being paid to influence individuals towards something that’s only beneficial to themselves. * I would like a community for people living with FASD or other cognitive and social disabilities living with neurotypical people in the community but are aware of and interested in supporting the residents. * Justice. * Neighbors offering help to disabled and welcoming individuals, conversations offering a helping hand if needed. * Support group with other young adults that have similar disabilities as me, Asperger’s. * A single person or entity to coordinate services (assuming there are any). Almost total failures here. * Someone who really gives a damn about me instead of just getting my messages off their desks. "Professionals" just don't follow anything through to the end anymore. * More inclusive communities, workplace support, and supportive groups. * More access to help. * AVAILABILITY OF RESOURCES FOR DISABLED SENIOR CITIZENS. * More public transportation- further and more hours available, more affordable housing options, more independent living supports, peer support for young adults, more young adult services- not children or seniors- young adults, benefits counseling and coordination * Safe * One agency that is responsible for coordinating the others. Every ship needs an experienced captain. Also, more for social interaction. Benefits are also confusing as heck * I would like to see a senior center with programs to help our seniors stay engaged. * There is such a long list that needs to improve that it won't even fit here. * More awareness and education * Being accepted, even when bad behavior occurs as it is a symptom of disability, not a choice. Having safe places to go, educating law enforcement, reducing negativity. * more housing, better public transit, instructions on how to get a better services plan, why do we have to fight for getting needs met/. * To have some opportunity to meet other families with disability children to exchange some information. * I'd like my life to go back to normal * None * Eligibility for loan with no credit * Not be allowed to speak to you direspect to make you ashame. * Better service at local cil * changes I'd like to see are more companies * People knowing each other more and shifting focus from isolation to community focus. Improved infrastructure for mental health. Wellness incentives. Community classes for differently abled persons (professional coaching, public speaking, cooking, driving) * Would like an evaluation of my needs in person and referrals for where to get help. * I would like someone to help me with all the paperwork I need to fill out . * Have People available to do yard and house maintenance * Ability to go places and be with peers * I would like to see government and agencies step up to make sure we are being heard and seen, that we are not forgotten because we live outside of the most populated areas. * peer support connections for caregivers; help for transitioning out of incarceration; earlier intervention for supports, education, coaching on self-advocacy with students and families(prenatal/infant/toddler/preschool/kindergarten/elementary and middle school ages) – including peer supports for families who are grieving, are dealing with mental health, IDD, brain injury. |  |  |
| Recreation | * More outdoor wheelchair activities * More inclusive adaptive recreation. More community awareness of different abilities of people. Safe, accessible, affordable community housing, not group home. CMH/PIHP’s to do their job providing appropriate services in a non-toxic, non-adversarial way. * More resources for post-secondary education, therapists, caregivers, and staff, and maybe recreational activities for people like my daughter. * More fun events for shut-in like me giving more social opportunities * More housing options; more social / recreational programs for young adults with mild cognitive impairments (maybe through the local Y center?); increased awareness of the effects of drinking alcohol while pregnant which results in FASD * More activities for the Physically Disabled * I would like to see more easily available resources for those of us with handicaps. More curbside shopping without a lot of added expense would be great. A handicap access to any of the local swimming areas would be wonderful. I'd also like to see more activities available for socialization. I'm not sure, maybe this last one might be out there somewhere, but I haven't found it if there is. I know there are many of us who are basically shut-ins, barely leaving the house except for appointments. It would be nice to get out and socialize from time to time when my health permits. * More low cost events |  |  |
| Relocation |  |  |  |
| Transportation | * Transportation * Self-selected free basic & essential services and trustworthy knowledgeable advocates, cellphone & internet training, transportation * Transportation * The local Commission on Aging used to offer rides to medical appointments to offices outside the county, where our buses don't travel. I'd like to see that service back. * Affordable housing and transportation * Door to door accessible transportation - and additional funding so it doesn't have to come out of CLS budget. Extended hours/days for community events (including weekends). Adapted programming that meets the needs of those who have more involved/complex disabilities. Tired of being left behind with little or no forethought in this population withing the disability community. * overall transportation and housing in the community and better access to those would be wonderful. * inclusion in every area for people with invisible disabilities especially; the county and state should work together with community resources to provide private rides for folks in special needs categories like sensory processing disorders and trauma disorders for example. Also, would love to have access to free or sliding fee scale regularly planned social activities; a regular home nurse visit and in-home mental health support for those who are their only caretakers. The community needs to be better educated on invisible disabilities so it can pool it’s resources from the area on aging (which needs to drop its age to at least 55), to disability network, women’s resource center, along with county and state nonprofits or agencies including DHHS should all be able to work together in an efficient way to provide much needed supports for its most vulnerable disabled population. I would love it if the local DHHS could assign me an individual caseworker that could set up a team of supports for people like me. * More dependable transportation, trainers for driver's license. Better opportunities for employment, equal pay for the employment. Savings plans for the future, and equal Medical Services for the disabled in the community. * More public transportation- further and more hours available, more affordable housing options, more independent living supports, peer support for young adults, more young adult services- not children or seniors- young adults, benefits counseling and coordination * More public transportation and more staff * updating the Canton transportation system.... offering rides beyond 5pm and potentially on some Saturdays. Transportation is very limited between seniors and * More affordable transportation * More local amenities. I have to travel 2 miles to the nearest grocery store. * More frequent weekend city bus service. More options for affordable rental apartments or condos in the city of Grand Rapids. * Assistance with transitioning into the community out of high school if college is not the plan. Additional transportation options. Assisting parents with knowledge of what now. * more housing, better public transit, instructions on how to get a better services plan, why do we have to fight for getting needs met * Make transportation more accessible.   Also, education concerning financing.   * Easier ways to use transportation money in Individual Plans of Service to be used for Lyft or Uber drivers. * More public transportation or even private transportation! More affordable housing options * Easier county wide transportation that is not age related. * More transportation options * Better access to transportation for those of us with a disability that prevents us from driving ourselves. * Free rides for the disabled to wherever we need to go. * Accessibility and Transportation * Bus stops expanded in Portage on Portage Rd Local organizations like Disability Network offering more help with transportation * Wheelchair Accessible Transportation after 4p and on weekends and Events/activities and openings in day programs. More outreach to those who are severely, multiply disabled. These individuals are being left behind * More transportation. Buses that go in both on directions without having to walk a long distance get to the bus stop that's going in the direction you need to go. More Sidewalks. * Extended routes and hours for pubic transit. Accessible walkways and outdoor areas. Affordable and ACCESSIBLE Housing. |  |  |
|  |  |  |  |
| **Life Area** | **Barrier** | **Input Source/Public Hearing Location: SILC IL 2022/2023 Community Needs Assessment Survey Question #4: What Services Would You Like to See Your CIL to Provide?** | **Public Hearing Date:** |
| Accessibility | * more advocacy with local government regarding accessible sidewalks and elevator maintenance (that might be owner of the building thing? but there must be a code they are breaking. Apartments in the old Central Bank bldg were broke for 3 months this winter and caused hardship to disabled folks in the apartments and us that would have liked to visit friends) * I imagine that there are places which need an entrance which is wheelchair accessible and elevators to supplement stairs, Although I haven't checked this and don't need them myself. * I would like to have a voice in how our state enforces or educates businesses to accommodate accessibility. Give more support to those with disabilities who are trying to live an active life in the community, especially those who are trying to work and not seek government assistance for routine compensation. * Information in a manner that is easy to understand and accessible * Outside doors that are automatic to enter, instead of locked |  |  |
| Assistive Technology | * Access to better assistive technology Social networking and opportunities Support in advocacy and activism * More involving assistive technology, supply and training * Financing for technology to support independent living, including remote support. * Employment support Community advocacy One on one help working on my goals. Help with technology |  |  |
| Education | * Help guiding through the different programs to secure a future. * Advocate & free services * More trainings for the experienced volunteers, support groups for women (broken down by ages (21 to 30) (30 - 45) (45 - 59) (60 and older) and men in the same age groups, sponsoring a once a quarter fun activity (bowling, miniature golf, etc) or a once a quarter holiday event (pizza and dancing for Valentine's Day, Easter egg dying and hunt, cook out / bonfire / maybe fire works for both the 4th and Labor Day, and a holiday pot luck in early to mid-December for both Thanksgiving and Christmas and maybe movies/snacks and a toast at the end of the party for New Years Eve or Day). * CLS Community integration * Advocacy & education of recipient right’s, customer service grievances, appeals process. I’d like DNL to be a third party 504/IDA coordinator with CMH. * How to get a ramp and door to door transportation for events I would like to attend day or night * Advocacy and skill support. Transportation * Coaching for people with disabilities who are aging. * playingforkps@gmail.com my email help with computer training and would like help with an business have mental health but not dumb. * Co-train support staff alongside of individuals and tailor the training to the individual needs. * Access to better assistive technology Social networking and opportunities Support in advocacy and activism * More peer supports * One thing I've noticed when calling them is a duplication of service that United Way 211already provides in regards to seeking information. For ex, I've called for resources and they literally provided the same basic info. 211 just had. I'd like to see them take a step further with a specialized database for the population they serve. Just as an ex. I can get food pantry contact info. from 211, but they may not know which ones are handicap accessible. The CIL should make it their business to know, enter it into a database for all providing such information to access & dissemination. It should not be hit or miss when you call & see what they happen to know or who's willing to go the extra mile, if they don't have info. * Educational options, support, and vocational support * A peer support parent to go to an IEP. I'm advocating they start that process at 14 years old. And educate and informed. I learned most of what I learned from other parents. But where are these other parents? * I would like to see parent peer support for like adults with significant disabilities aging out of the school system where they fall off that imaginary cliff and are struggling to find services. And not panic about what are we going to do? We are aging. We don't want a group home. What happens next? Like a parent support circle. To even go to each other's person-centered planning and say well, this worked for us, hopefully it could work for you. Or try this, try that. * Help with explaining the services and how they can be applied for and understand * Finding and supporting housing needs. More vocational training options, MRS does a terrible job here in Washtenaw County and we need more vocational training and job coaching/support opportunities. * Computer classes. * Help with drivers education for neuro divergence and/or support in finding affordable and accessible transportation. Help with executive functioning coaching and adaptive life skills improvement that are measured more regularly. * I would like to have a voice in how our state enforces or educates businesses to accommodate accessibility. Give more support to those with disabilities who are trying to live an active life in the community, especially those who are trying to work and not seek government assistance for routine compensation. * Advocating for people with mental illnesses along with people who live with disabilities. * Programs that actually provide peer support, activities and continuous educational opportunities and life skills to those with disabilities. * Job support, hobby and leisure activities for my peers and I that are geared to our abilities and interests. * Our community needs child advocates to help families navigating the IEP process with the schools * more school to work transition |  |  |
| Employment | * Support in finding housing and employment * Job coaching. * Like I say, I was in a coma two and a half years ago and I progressed so far and so over coming, you know, like I say I've only had SSI because I was a builder and a concrete manager all my life. But over the years I kind of went off on my own and was not paying into the taxes. And so that's why I got SSI instead of, you know, the actual support. But anyway, so I'm kind of curious to know between SSI and how many hours I can work, you know, if I actually live somewhere I can be a maintenance man. So kind of wondering you know if I can get some kind of place to live that I can be part of the maintenance company and you know help with my rent. * Idk what is out there. Shortage of nurses, no job, I cannot get on my feet. * More inclusive and long-term supportive employment options which are currently being taken away. * Social gathering places, places to volunteer or work to have a purpose. * Job support, hobby and leisure activities for my peers and I that are geared to our abilities and interests. * Help with living skills, but not like talking to people like we don’t know things. Talk to FAS adults like regular people. Life skills in school was not good and they talked to us like we didn’t have a brain. And, help finding a part time job. * Employment services like coaching, independent living services like finding housing that's affordable. * Disability inclusion education geared toward employers. * Employment support Community advocacy One on one help working on my goals. Help with technology * Anything that actually helps. My CIL center is disability network. They just tell me go to voc rehab again. I can google that myself. * Professional support reentering the workforce after a cognitive change. Public speaking support. Driving support. Specialized psychological support. After discharge from services (PT,OT,Speech, vision ect) more wrap around support is needed to coordinate ongoing care at home/work. * Stronger push for Competitive Integrated Employment and solidarity in the phase-out of 14cSub-Minimum Wage laws. CIL provided de-escalation staff to accompany and "ride-along" with Law Enforcement. Employment placement and support, personalized education assistants to assist students who aren't receiving as much individualized time in mainstream education such as providing 1 on 1 time, or proper resources the student would need to feel most prepared. * Entry level jobs for Disabled people, computer class, art classes, and outdoor living activity classes/groups, more community events to be with others with disabilities. |  |  |
| Health Care | * home care in my own home so it keeps me independent less germs dependable transportation * better home care services * We need reliable agencies that provide QUALIFIED 24/7 direct support staff so adults with autism and higher needs can live independently in the community * We need case managers and workers who stay with us especially as our parents age and die. As a person with little to no way to communicate it takes a long time to get to know me and usually a person is gone in 6-9 months so I do not feel safe * Advocacy, peer support, getting on supportive housing waitlists, brain injury support, financial assistance/supports, individualized vocational rehabilitation, help with setting/reaching goals as in service dogs or access to animal therapy. * Idk what is out there. Shortage of nurses, no job, I cannot get on my feet. * Testing services for adults for disabilities such as autism. * Actual help arranging my medical appointments and medication supplies, 20 hours a week house/yard Maintenance help and a TRUE advocate to navigate the system and cut through the BS. * Frank information about money for Community Living Support funding. Resources to find train and retain staff. * More advocacy to CMH/PIHP’s to provide services mandated by contractual requirements. CMH/PIHP’s follow technical requirements and policies. * Caregiving support in an independent living * I'd like to use respite service if there is such thing available.   So that the person with disabilities can go out and have some fun even both parents are busy working full time.   * outreach to patient's homes that need in home help with daily tasks of living like color coding files so they can find them, advocacy and help filling out and explaining insurance forms and finding appropriate docs, weekly scheduled fun activities with peers like A2 CIL does, helping with financial empowerment that takes clients interests and unique situation into consideration, a special program for disabled and chronically ill folks who are their only caretaker perhaps having a safety center specifically for those individuals * I need some counseling with aging issues and someone to talk to me about PACE, and what it entails and if I qualify. I know I am at risk of nursing home and qualify age wise next year 55. Some illnesses are progressive. Husband and I are worried about aging issues, do not have family support. Area on Aging, some stuff is complicated who to go to first. My local CIL has HELPED me on many issues and glad they are there. * home care support services, information and referral * List of workers who have been vetted * Data collection of the number of children and adults in Michigan each year. Data on what types of services are available in metro and rural area.ie evaluation and case management. * Mental health support. Mental Health support groups. More online support groups. More funding for in person/hybrid support groups. Free transportation to support groups. Opportunities to volunteer with a group with transportation provided. Help with Medicare questions Help with low income challenges |  |  |
| Housing | * For seniors 70 and older with income less that city median income, provide rent control for better accessibility to affordable housing, and/or for primary home provide free sidewalk snow and leaf removal and subsidized home repair services. * Transitioning to an apt by myself and not sharing with others. * Advocacy to assist the disabled and elderly to find and afford housing. Also, advocate for more mass transit. * Housing and staff! * More first floor housing * Funding for housing * Support in finding housing and employment * Better housing options which would include independent but supported residences. In safe neighborhoods. * My grandson with PWS is a teen and we have begun researching safe living situations. None available in Michigan. * Put access to a listing of housing options and funding sources. * Like I say, I was in a coma two and a half years ago and I progressed so far and so over coming, you know, like I say I've only had SSI because I was a builder and a concrete manager all my life. But over the years I kind of went off on my own and was not paying into the taxes. And so that's why I got SSI instead of, you know, the actual support. But anyway, so I'm kind of curious to know between SSI and how many hours I can work, you know, if I actually live somewhere I can be a maintenance man. So kind of wondering you know if I can get some kind of place to live that I can be part of the maintenance company and you know help with my rent. * help with affordable housing stabilization and planning a move to an area where I can get more than 1 of my 8 vital support needs met. * Finding and supporting housing needs. More vocational training options, MRS does a terrible job here in Washtenaw County and we need more vocational training and job coaching/support opportunities. * Advocacy, peer support, getting on supportive housing waitlists, brain injury support, financial assistance/supports, individualized vocational rehabilitation, help with setting/reaching goals as in service dogs or access to animal therapy. * SUPPORT FINDING RESOURCES FOR HOME REPAIR AND TRANSPORTATION SERVICES * More Accessible housing options. * housing counseling/assistance, benefits counseling, social opportunities * To see is pushing the narrative that everyone with a disability needs to live in Community based living opposed to Advocating for individuals with the disability to have their homes modified so that they can reside in their single homes. * Living options * idk what that means i brokemy skull five years ago lost my career most of my body movement i knw my son and i would be happiest on the sable st home in alpena instead of 3rf and its quiet there and laundry mat next door * More help with getting on section 8 and getting more affordable and barrier free housing in the community. * advocacy for low cost disability housing * Employment services like coaching, independent living services like finding housing that's affordable. * Opportunities for ‘community’, in addition to housing. * Assist in developing housing models that promotes life long independent options. * Housing support, maybe roommate matching or a housing directory for younger adults * More income based housing options. * find suitable home for rent. * Advocacy, change in stronger Housing laws against bullying disabled residents * help with rent * I’m needing help with purchasing my own home. * Look into what some areas have done to develop shared ownership residences or communities(communes), where a group of older people buy a large home that they share, versus a commercial, expensive for profit assisted living residence. They are thus able to afford and enjoy independence with companionship and be in control of services like meals, maintenance, personal care, etc, at much lower cost and higher quality of care. There is a successful model for this in Toronto and also in the western US. There are also public services that screen for successful “roommate” home sharing especially in areas that face housing shortages, college towns, etc. I would be happy to discuss further. * better connections with housing resources and better communications * Home modifications inside of one's home |  |  |
| Other Supports | * More help for limited income people. * Any help for disabled (SSDI) folks w no kids!!!! We have nothing! * Consideration of rare conditions and how these needs limit access to (and usefulness) resources in the community. * Just basic required, core services would be a start. * Thankfully, there are things like a local restaurant in Saginaw that has curbside service. Pharmacies that deliver medicines. Curbside delivery of groceries at Kroger’s. But they are so few and far between. * More resources for those who need 24/7 care and a high need of support. * Day programs that provide personal care and social opportunities. * Grant writing support and advocacy for better pay for caregivers and home modifications * Help me to get set up with help * Housekeeping, paperwork, help with finances , cooking, help with monthly transportation, training for more (but never total independence. Help with state and federal paper work. * Anything that would get me out of my house! * No CIL in my direct community * Help with Financials, help with medical * Coordination with family when issues arise. ALL members of family which in my case being co-guardian they rarely call me when there is an issue calling her mother first. * Counseling, chore service, snow removal, rides to doctors. * Parent support groups for aging caregivers with highly complex needs adult children. The “misfits” who are too challenging for day programs and aged out of ISD. * Work aides Adult Day center * Some type of supportive care that is consistent and for higher functioning. A place where he can go for a few days a week. * Something after graduation. * Services for guardians to drop there clients or young adults for a few days so we can regenerate ourselves * I am not poor, but major expenses like bathroom safety upgrades can be exorbitantly prohibitive. I have fallen in my bathtub twice, but the cost to change to a walk in shower is$12k to $19k. I can't shovel snow but not even the local senior center can tell me who might shovel my walks, even if I pay them. The same goes for mowing my lawn. * What is a CIL. wTF? * We need more options for parents to give opportunities for their children. * idk * Service’s for dealing with Social Security. * Information and some central place to call for that info * Maybe system to contact trash hauler identifying disabled person in house needs trash can assistance. My neighbor may move soon. Very distressed about next step to find help. * Everything listed above. * Respite, other ways to save money for bigger expenses since you can only have $2000/month savings * I would like my CIL to keep providing the services they provide. * Funding a real concern as well. * Add the visual map, that would be very helpful. * It would be ideal if there was more connection to school districts or places that have these young adult programs. So that they can provide information, ease of transition. I'm part of a group called the Washtenaw life span which is a bunch of mainly moms trying to develop all these things that we are talking about. You know, what is happening after age 26. Where are they going to go. So you know, and, again, I'm a newbie and I'm learning all this but it's like we have to hunt and Peck for this stuff. And there's so many places to hunt and Peck. That it's like there is no one place that we can go that would find or that would help us with all of this stuff. * In fact, there was a parent in the school district who put together steps once your child turns 18 these are the things you need to do. And that was made like, you know, 15 years ago and it's still being used by people. There is nothing like that out there to tell parents of students who are transitioning into the young adult, or you know, transitioning out of the young adult program, what do they need to do? I'm just finding it, you know, through things I get in the mail. Or I mean it's like and it's overwhelming. * It seems to me a well-kept secret that about Disability Network lakeshore or I've been unaware until about a year ago that this agency exists. * The one big thing that I would like to have is, you know, the healthcare advocacy and help with healthcare management. But I think also something that would be, I think, just overall much better is if the Disability Networks were working directly with the disability rights organizations. Because that is something that I see a lot where people, you know, individuals are bringing up these issues that come down to like a public policy issue or a legal issue and then they just get sent as an individual to disability rights organizations for legal assistance. And then, you know, whether or not they pick that up as a case or not, but then on these larger, because a lot of issues that I have I can recognize them as systemic issues within, you know, the healthcare system or within the community that aren't really, you know, it's not an individual issue. But then the Disability Network can't do any type of like legal work or they can't do policy advocacy lobbying type work. And so there is just this real gap where it's like, okay, we don't have the legal framework for this yet, but we have this need but then they can't carry that over to the legal arena when it's not just an individual issue. * And that I know the center has helped me with like our community pool was charging a $2 caregiver fee for a person who needs assistance to go to the pool. They help do away with that. But that's how I found out they have an ADA504 coordinator. And I feel CMH needs to utilize that person's knowledge more in the advocacy realm versus all this internal CMH making all these decisions. That each CMH having a contracted ADA 504 coordinator. * In our area I would love to see more independent supports coordination. * Would there be a conflict between what our CMH people do and what the center for Independent Living people do? Because I feel like one would one supersede the other because I've heard the center for Independent Living can do, supports coordination which is what CMH does. So it's all confusing. * And, you know, this is one of those things where I struggle. Because what I would like to see them provide and what he would like to see them provide might be two different things. And so, I think part of that is really making an effort. And it's not easy to communicate with people who maybe have an intellectual disability to figure out truly what is it that they want. What is it that they need? And I know that is going to require some partnership. But what I think he needs and what he thinks he needs are probably not always going to be the same thing. He's lonely. So, if there was a way for a center for independent living to provide, gosh, I don't know, some authentic community activities, I love what Cincinnati does. I can't remember the name of the project down there. And it's been a while since I followed them. They really do, you know, for example, if you have somebody that, I don't know, likes to drink beer you know then they will have a night at a local brew pub. And invite lots of people to come. Not just people with disabilities. It's something that is more authentic to the person's interest. * Training. * Advocacy, peer support, getting on supportive housing waitlists, brain injury support, financial assistance/supports, individualized vocational rehabilitation, help with setting/reaching goals as in service dogs or access to animal therapy. * Essentially living without fear or without control. * Whatever you offer within regulations. * I am without money, and I can't get any support emotionally or with Justice and I don't know how long I can stand by and watch my son regress cognitively and emotionally. It's too hard for him to bare, yet I can't find any hope to get him home. I feel like I 'm just made to watch this living nightmare happen to my boy, and even he's given up on me, as he was there, he saw it all. He seems to have lost respect for my role as a 'can do' parent. I feel like I'm stuck with this life powerless. * What is a CIL? * Actual help arranging my medical appointments and medication supplies, 20 hours a week house/yard Maintenance help and a TRUE advocate to navigate the system and cut through the BS. * She cannot and will never be able to “live independently “. So, unless CIL has resources that focus beyond that… really not sure how they can help. * Many. * housing counseling/assistance, benefits counseling, social opportunities * Help with living skills, but not like talking to people like we don’t know things. Talk to FAS adults like regular people. Life skills in school was not good and they talked to us like we didn’t have a brain. And, help finding a part time job. * One agency that is responsible for coordinating the others. Every ship needs an experienced captain. Also, more for social interaction. And help with finding benefits and understanding how to apply. * A platform for building a natural supports community for each person that allows personal autonomy and a universe of chocies for a turly free life. * it would be so helpful if the AACIL was able to slowly reopen so that we could have more services provided in house - able to reconnect in person with other disabled individuals... provide services face to face. It would be great to see a plan in place for reopening of this facility. * More supports * All the above and much more. * Expand support group topics. * What is CIL? * Opportunities for ‘community’, in addition to housing. * Local systems change opportunities for citizens * She does not have a CIL. Not sure I know what the c stands for. * One on one support, caring discussion and tempered redirection. * i don't think there is a CIL in my county * I'd like to have my CIL services to better when people call in and I'd like my services from another CIL * Anything to alleviate the burden on parents/guardians. * Internet, etc. * All the above * I need help around the house my home is getting old and every thing needs redone . Rides weight loss * All the bedr * Anything better than Kent county provides. * Financial aid for independent living especially if you are ward of the state. * I would gladly accept any of the above services. * Legal advocacy I’m seeking help in regards to my home. I’m in fear of losing my home. Upon review of my title work on file at the Berrien County Register office I became aware of several fraudulent titles. The grand total is over $500k. No one in their right mind would extend a legal mortgage to me: 1. Property value is not even $200k 2. I’m permanently disabled with out any cash infusion on the horizon. 3. My husband died so I’m with out a second source of income to pay down loan. 4. My current housing circumstances have created an very tenuous environment that threatens my health.   5. I’m financially and physically unable to advocate for myself. I have approached this matter from numerous directions. I stuttered which impacts my communication skills. I have tremors causing access to computers almost funny. I have three areas found on my brain making it difficult to recall, remember, and endure constant migraines.  6. I’m mocked on a regular basis if I need to explain why I can’t just do it myself. I’m beg you upon considering my request that if not in your area to refer my request to an area more appropriate. Sincerely in Christ, Andrea L Struble 661 Tucker Drive St Joseph Michigan 49085   * I appreciate peer support offered at my local CIL. Recreational opportunities are great to have. * Help * There is no CIL in my county * Bathing. Cleaning * Help with all the paperwork, it is too stressful for me. * Day programs for adults with disabilities that need assistance to participate. Mocha, spectrum won't provide the support and have excluded me. * I'm really not sure since I have not worked with a CIL. * My Cil is a great resource with lots of programs and projects |  |  |
| Recreation | * An adult day center that operates Monday through Friday, 7:30 am to 5:30 pm, that provides care for those with high level needs, offers community engagement opportunities and other meaningful social opportunities. * housing counseling/assistance, benefits counseling, social opportunities * One agency that is responsible for coordinating the others. Every ship needs an experienced captain. Also, more for social interaction. And help with finding benefits and understanding how to apply. * Transportation to apts and fun events, like swimming with a group in summer, and other outings in the fall and winter. Maybe ? parties * Social events * I'd like to use respite service if there is such thing available.   So that the person with disabilities can go out and have some fun even both parents are busy working full time.   * I appreciate peer support offered at my local CIL. Recreational opportunities are great to have. * Entry level jobs for Disabled people, computer class, art classes, and outdoor living activity classes/groups, more community events to be with others with disabilities. |  |  |
| Relocation | * Advocate. Skills peer, transition to community based living * Education with a focus on DWIHN Residential Department staff (there is a bias / preference for segregated, congregate care - licensed group homes in Wayne County. * Transition services with legal system; online resource hubs |  |  |
| Transportation | * Advocacy to assist the disabled and elderly to find and afford housing. Also, advocate for more mass transit. * home care in my own home so it keeps me independent less germs dependable transportation * Transportation, especially in winter, to social, cultural, and educational programs. * Advocacy and skill support. Transportation * Help with drivers education for neuro divergence and/or support in finding affordable and accessible transportation. Help with executive functioning coaching and adaptive life skills improvement that are measured more regularly. * SUPPORT FINDING RESOURCES FOR HOME REPAIR AND TRANSPORTATION SERVICES * Transportation to apts and fun events, like swimming with a group in summer, and other outings in the fall and winter. Maybe ? parties * Affordable transportation * Transportation |  |  |

Question #5: What have we not asked your experiences with Independent Living that you feel is important?

Being married & both SSDI, we get ZERO help. The township screwed up our taxes when we moved in....so no escrow, we've got to save for taxes...so no help!! I'd be happy with some fresh produce once a month!!!!! Our bills are paid, but that's it.

If advertised help is really, in practice, available.

We need help figuring out how to find a way for our son to live in faculties and situations with others, not just people with the same rare condition, because there just aren’t enough people with this condition to provide independent living options within the state of Michigan. Please help!!

Do you have someone to talk to who listens to and believes you? Do you make your own decisions about your life? Do you have control over your finances? Do you have a trusty lawyer and tax preparer?

The Board of my CIL is literally comprised of a majority of current or former sheltered workshop managers. That's a huge conflict of interest that is demonstrated in their work constantly. They partner with the systems discriminating against people with disabilities and directly retaliate against any advocate who speaks up about our rights.

A sense of being able to do things when you do not have a partner or a friend. So much of what I do I do alone, and it is becoming increasingly barrier, defiant.

Independent living vs living in a group home setting or w/roommates. Independent should be one not more than one living together.

Consistent volunteers should have more input into how things are done at the C.I.L.'s in terms of how certain programs are done and not the way things are done according to the C.I.L. board or the executive director.

Supportive employment Alternatives to MRS to stay in my home and not be threatened or put down or called names to be stretched assistant basically.

none

Help paying bills.

My area is weak on advocacy and information. Kalamazoo is super strong with information & education.

The local CIL seems geared toward those who have higher functioning levels

There is a lack of home care providers, therefore families must quit their jobs to care for loved ones without pay or with minimal pay that can’t support a family with a member who has special needs.

Home sharing can work to keep seniors more independent at home. Vetting potential roommates, and having examples of agreements between seniors and roommates would be very useful.

Nothing

What do recent lawsuits awards for MI Medicaid failure to provide care services mean for the community? Is better pay coming? How to get help?

That he can live in independently with enough supports and the paperwork is onerous. It’s punishing to parents like me who do everything and the paperwork is the most stressful.

For those who need daily medical care but could otherwise be independent. What does a person have to do to get hooked up with this service? Is it Medicaid based?

I do not qualify for Medicaid. Being disabled is expensive and I avoid doctor appointments so I can pay my rent of $740. My disability is $1250 a month. Expanding Medicaid and making housing more available is desperately needed.

I an my kids have a very complicated issue that seems to be a gap in support form. I cant seem to get the supports needed anywhere for myself or my children both disability wise and as victims of abuse/sexual abuse (for my kids). Please reach out to me atnataleegroesser@gmail.com so I can go into detail. Or 2314994379

services needed and funds available to remain in my home not requiring moving to a nursing to survive. Also availability of funding for middle income individuals so families are not shredded by a need for extra supports Recognition of dementia as a Disability high needs support and is like a car accident, something not necessary planned for! Monroe independent living needs help in general

SEX!!

Being in assisted living the societal influences of peer pressure. Also low trained staff unaware of the realities of dealing with the cognitively impaired.

Housing

I have concerns for friends ... Getting more inf from SAIL and maybe some info/posters about your services that could be located in coffee shops, library, etc.?

I would like more advocacy efforts to meet the high intensity severe Autism population with aggression. It’s too hard to find providers to work with this challenging population.

I just want to live in peace and harmony I think everybody has that right mental health and fair treatment we're all human we all have issues.

It is incredibly difficult for those who don’t meet requirements for programs such as PACE to find options that are sustainable. Legislative change needs to happen to either allow people to earn some income to pay private care or programs that are based on physical attributes and not age based. Many people are single and need resources to be able to remain in home. Insurance should have to provide prior auth info for large purchase DME items such as powerchairs. Having to make a 38,000 purchase not knowing coverage or out of pocket cost on limited income isn’t fair. Advocacy and laws need addressing.

To learn how to take care of yourself right in the real community

I attend the CIL in Lansing and sometimes we do not have our meetings because MCRS meets there and uses the large room. I think that PWD should be prioritized and that their activities should not be cancelled because of a government meeting.

How to help me develop friendships.

My mom has three of us and my dad is gone. She has started a non profit to create a home fo rus but gets no state support for this endeavor

Getting groceries. Paying bills. Getting to events that cant be navigated alone with a person in a wheelchair, affording rent. Limitation of current costs when you can only have a savings of$2000/ month. How can you save for a car, rent, repair expenses etc

Concentrated outreach even if it's through CMH, PCP's office, ISD's, Schools, Churches, County Government, Social Security, DHS. Get the word out so everyone is informed. Create more awareness.

Class in high school so people know experience of struggling with disabilities. So hopefully more helpful

If you receive benefits from government sources you usually need to sacrifice your privacy and give a state or county employee a personal profile that is invasive. Once you have a caseworker you are halfway toward being institutionalize in a hospital or prison.

We need reliable agencies that provide QUALIFIED 24/7 direct support staff so adults with autism and higher needs can live independently in the community

Just very difficult for guidance as to what to do next in life and transportation available for people too scared to ride public transportation

to be better at home care services

How easy or assessable was/is it for you to find affordable housing? And should their be an increase to SSI benefits & should laws be changed around SSI amounts currently rec'd, inheritance of property, etc. It's as if ppl on SSI are being punished because of their disability.

Not sure.

When I was a social worker (before I became disabled & unable to work again), I'd want to refer appropriate clients there, but could NEVER get details on how they could help them. They need to do a much better job defining exactly how they can help people. Now being a client, I haven't seen much improvement. I should be able to see, at a glance, what they can do to support me. Sometimes I have a need & don't think anyone can help. My local CIL should be a no-brainer go to resource & if they can't do it, they should absolutely know who can. We typically only have very similar basic needs- so they should hands down be the expert here. There website needs work, too. It says click on these for additional resources for ex. for food assistance & they lead nowhere. When I pointed this out, they said an outside company handles & they can't modify. The link less options remain. Also waited a significant time period to get a response thru FB Messenger & a question on a FB post...why have these as options for communication, if they are not on someone's task radar to respond in a timely manner (I waited around a week, sent a message again & finally got a response after a couple additional days). Just not acceptable, in my opinion. Yes, I could have called, but if that's the only/best way to get help, then don't make others an option. You can modify a FB page to not accept direct messages & provide the contact number instead. Thank you.

Just need more independent with supports living options.

This is a poorly designed survey, seemingly designed to check a box vs gather meaningful data. I am embarrassed for you.

idk

I live in Wayne County, but Disability Network of Wayne County is 1 hour away, so I can't attend programs there. Disability Network of Washtenaw/Ann Arbor is about 40 minutes away from where I live. Consider bringing programs out to day programs.

Nothing affordable, not even In the ghetto anymore.

You might ask if I have any difficulty in paying everyday expenses. I don't, but I imagine some people in this neighborhood do.

That you work with cities to at least not fine us if we can't shovel our snow or if the grass gets longer than we like.

We need to know that we can trust people working with our children.

We need more accessible places for adults to go - whether it’s a day care for respite for their care givers or a safe place to live once their guardians have passed

I feel we don't have adequate services that promote independent living for the vast majority of disabled adults in the Thumb of Michigan. We have wonderful special needs schools but after the individuals with high level needs graduate there are no options available that provide similar care and engagement. Those adults often end up in group homes, or in their family home where family members are forced to leave the workforce to care for the disabled adult. It forces those families into the "system", no longer able to work, reducing their way of life, and relying on government benefits to support the family. If a day center were available that could care for multiple disabled adults, their families could remain in the workforce, providing a quality standard of life for the family, and be productive members of society. The disabled adults would still have stimulating, meaningful, social connections which helps to maintain their mental health which directly affects their physical health.

The disability network office in our area seems to be anything but helpful… Very disappointing…

Why don't the government offer more help for people with disabilities.

Being lonely is a huge factor in quality of life. While I can have the independence and choices through independent living and self-determination, I can still be lonely and that is a barrier form e.

The options that are available to our community members are limited and not always in the safest communities.

When an individual gets a job interview for whatever job they've going for, and the job interview is such that they can't take the job because the employer is unwilling to provide the assistance to be able to get to work or have the assurance that you're being able to go to work because you're disabled and need assistance, getting up or getting dressed, or whatever it may be, that situation in itself needs to be addressed. However that works between the employer or between other supports in the community to provide the funding so that the person can work and still maintain their quality of life would be wonderful.

Need to be in locations with access to public paratransit services and paratransit needs to be more reliable and also to cover routine services for employment.

We have the realization that the least restrictive environment for one individual might not protect the needs of an individual. Need different provisions for different people. Rare diseases make very rare needs.

People with different disabilities often receive different services.

Just awareness that they exist and what they're capable of doing. More awareness of what is out there.

And what they are capable of doing. Because most of us need help with advocacy. But a lot of advocacy organizations don't it's more action versus talk. And changing some of these systemic issues. And a lot of times it takes a formal complaint, a formal appeal, and a lot of us don't know how to do that or where to do that and just to have some moral support and encouragement to make this world a better place for people with disabilities. Because another information and referral to somewhere else is time consuming and exhausting when if they are here locally, could help more with local efforts.

I can tell you that they have always been responsive. Whenever I have reached out to them with a question, they have always been responsive. Very pleasant people to work with. We are a subsidiary down here; I think of Ann Arbor. Or the Washtenaw, I can't remember what they are called, Disability Network. And so, I'm appreciative of that. If they don't know the answer, they will try to find it. Because we live in such a rural, rural area I think transportation is a big deal. I don't know how they can help that truthfully. I don't know that many people have the answer to that one across the State of Michigan in urban areas as well. But transportation certainly is a huge barrier. And then I would like to see some more guidance and support on how can you make a home, what's the word I'm looking for, more adaptable. And accommodating. With, you know, kind of like some supports in a local level from, let's say, like the Disability Network of Michigan. No, that's not what I'm talking about. The disability rights coalition. I would get them, and Michigan disability rights and disability rights Michigan confused but I know they have an assistive technology person up there. It would be nice to have something like that at the local level that you could go in and talk about, you know, an example would be showering. It's really, really hard for him to adjust the temperature on his shower. And so, what are some low cost…I know there is 2000 devices that you can break a wall out and install and have that work. But what are some low-tech areas that you could implement to help him maintain his privacy and independence. Stuff like that.

Would like to see more people with disabilities in leadership and decision-making roles.

The lack of supports in my homestate for me. My main professional supports are out of state and my out of state supports are horrified at how I am just left to do everything on my own here and how I am beyond burntout and it's not fair to the out of state supports either.

Being able to reconnect with my family.

Acknowledging the DCW workforce shortage is critical.

Supportive employment services such as crew work through agencies with job coaches and advocates on site are crucial to independent living for many individuals. The way things are currently going, those opportunities are slowly being ripped away.

You say you support it, but you don’t. Not enough resources and you don’t understand our needs. Our needs aren’t always to be shoved in the community where we can’t function or have severe anxiety. Some are more disabled and not able to participate so they are segregated at home. Talk to parents and caregivers about what is needed, they know more than your reports and articles you base your programs off.

You neglect to ask if it’s even possible. Not all reach that level of the spectrum where they can live independently, work a job, make the best possible decisions, etc.

A few of my health issues; Lung cancer in remission, kidney transplant with new kidney failing due to malpractice, surgery needed on my back, hip issues plus arthritis in knees, hips, back and hands, Long covid causing brain fog, CPAP, breathing issues, serious diabetes, bad teeth, need eye exam and new glasses, poor hearing, neuropathy and so much more.

How to get started. I’m adrift with almost no help. Kalamazoo area.

If my caretaker needs a course on what helping someone like me means. I don't think he knows.

It's not independent living, that's the issue; it's having to live through this at all.

?

Why do physically or mentally challenged families have to sacrifice more money, time, and effort without assistance than others that are not? Why doesn't the State or Federal Government assist more?

This needs to be affordable and not work against the governmental assistance that they may be receiving.

It’s hard to maneuver your website.

If I understand Independent Living, what being independent means to me and how I might feel that the social community impacts or I should say influences our rights. Although I guess I have expressed some on what I feel is important without being asked and in my experience having a voice to be free to express yourself is part of being independent free of discrimination free of fear that you won't have a place to sleep a meal or even a voice to parent your children.

Team support for those of us with high maintenance and special needs disabilities who have no family or friends able to offer any type of regular support or assistance. Minnesota is the role model state here for this type of care to keep disabled folks like myself in our homes as long as possible. I lived in Minnesota throughout the pandemic so please feel free to reach out to me for more information or details in this area, I would be happy to share.

HOW CAN YOU ASSIST SENIORS WITH REMAINING IN INDEPENT LIVING IN THEIR OWN HOME?

Improved transportation and travel needs.

Bathing, washing, changing, feeding.

It should be required for local Police, Sherifs, Fire and EMT to yearly meet several non verbal individuals as well as other individuals with other disabilities so they can learn how to serve these types of people. The state should develop and require trainings on how to identify that a person is mentally disabled not on drugs I order to protect these individuals from Police escalation due to lack of response to commands and also lack of verbal communication.

the lack of coordination, the trap of agencies= get support but not enough to be independent or if you are too independent you lose necessary supports

It would be nice not to live with my parents all the time.

I have no one to ask or help me out

Advocating for individuals with the disability to have their homes modified so that they can reside in their single homes.

Knowledge

Why isn't someone actually doing something instead of just talking about it.

Independnet Living has certainly expanded from its birth. But, it reamins more abstract thant the hopes for it over th elast few decades. Also, although the services vs. advocacy question has softened and become less binary, it is still there, and it still needs to be expanded into concreate reality. It remains the cutting edge of the best that Independent Living offers.

Support groups for families.

I'm sure there are so many other agencies and services that are available in my area, but there is no 'convergence of information' whether it be through the AACIL or local doctors, other agencies. It seems like often we find out information by accident by someone else who has run across something that can be of benefit to myself and others. I'm hopeful that more and more communities will determine to provide more disability housing that's not just designated for seniors. I'm not sure what that would look like but I'm sure it would involved financial incentive to builders to make these accommodations. Also, the Section 8 option waiting list is so long it takes years to get on a list. And if you're lucky to get on the list it takes years before anything is available. How can this be restructured both for potential renters and streamlined for landlords etc. Also better partnering with local Housing Commissions to coordinate services.

somedays the bad days with bad weather i get sever migrains and vomit cant get up to clean or get dressed i do need a in home nurse just 2 or 3 days a week my neice says shell help n i dont want anyone in my home idk ive had a very trumatic life im trying to salvage my son before his anger takes over and well have our own place with new good healthy happy memories if not ill be getting kicked out of here rents 1250 plus utilities idw waste on rent when if i bought the house now i can have it paid off right on time

Proving more money. Many CIL's are funded through grants and when the grants dry up, many of the talented or competent staff lose their jobs. It's frustrating when you go in for help and have to almost start all over with a different staff person who may not always know how to help you - in other words maybe you need help with ssa forms but get from the community organizer

Please research how many section 8 vouchers in Michigan go toward people with intellectual and developmental disabilities (I suspect the percentage is low). Put pressure on the state to change that, even a class action lawsuit if needed as people with the higher levels of need are still entitled to tenancy rights and it isn’t happening. The priority population (those with the highest intensity of need) should be getting the first preference for housing support and subsidies.

How to increase social opportunities, including transportation

Not sure what to answer here.

nothing

How can individual families be helped to achieve successful staffing if they need government support but are able to provide some financial support. It would be helpful to a lot of middle income families with some reasources to find a balance between total government support and not being able to get any government ie CLS support.

CILs are the only independent, flexible, support organizations, especially in truly rural areas of Michigan and that is north of M55. This is the only provider of assistance in many of these areas. More funding is needed, less bureaucratic red tape and barriers. Especially with MRS.

Medical practitioners that provide services via Medicare and/or Medicaid. Also mental health therapists who ‘get’ living with disabilities!

The MiABLE account has been difficult to set up.

Thank you

Hopefully resources will be utilized appropriately to provide appropriate Home and Community Based Services.

None

Rural Uber support for getting to appointments that is wheel chair compatible.

Most info I have found out from other parents who are not always sure either. :(

How to connect people with similar interts so we can work together to achieve shared goals.

Our son is capable on many levels but when meltdowns occur which they always do, he needs to be safe to get through it, not punished.

cils needs to be better with their clients and the desicions they make in giving former cils a chance

How can we help a person towards living on their own? How can we help them see what it will be like on their own. Practice housing etc….

I think it is important to support the parents as well as the individuals with special needs.

Is my local CIL offering me programs that are inclusive and empowering on a regular basis, if not why not?

Emergency plan preparedness.

My game skills.

If community housing is appropriate or comfortable for my disability.

I don't no the answer

None

There are too few services geared toward young adults. There are lots when you are in high school and lots for seniors, but almost nothing for young adults.

It looks good.

The lack of centers on the west side of the state.

Section 8 vouchers need to be open or have more funding.

Im just becoming aware of this program so im unable to answer right now.

It is hard for me to keep appointments and managing them is stressful.

yes

How can I assist my sibling with these needs from 500 miles away?

I think I should be able to have the support services that I need and want

Connecting with peers, Invisible disabilities, Education public,

You haven't asked how people survive if they have no family or suppport system to help them. You don't ask specifically about people on SSI which again is very different from the other program. We have a much harder time with literally everything and it;s beyond frustrating that the people who are supposed to help you know less about SSI and it's rules than I do

Program cuts and lack of staff that understand. Not peer related

Video library on how to get a better PCP and what to do if it's not being followed. Microbusiness support

Basic needs met.... my disability is Relapsing -Remitting Multiple Sclerosis, Seizure Disorder, Bi Polar/ Dual Diagnosis Disorder

I believe that CIL's should offer services that enrich the lives of their consumers. Recreational and social services are a great addition to my local CIL.

What has been your least helpful experience

Nothing I can think of at the moment but if I think of anything I will call you.

I was kicked out immediately effective Same day because I had a guardian and conservator. Not just a conservator.

Financial services

have a seperate housing booklet with vacancy.

The education side of my CIL is fantastic. They have learned the functionality of my disability and educate others about how invisible barriers, just like nonapparent disabilities, are still impacting us so that we are no longer invisible. We are included on the education side. On the advocacy side though, that has been a very different story. As I'm watching my health deteriorate due to lack of care, I've been told some abhorrent things from the advocacy side of my local CIL, including: 1. I should try harder, as if six years of constant work for a dental cleaning isn't trying hard enough. 2. I should travel further if I truly want care. I need care in my community, but care outside of my community also isn't accessible, so location doesn't matter.3. I should explain my situation better if I want care. When I explain my situation better and am still refused care, I'm told by an CIL employee that I'm 'off-putting' because I educate about my disability. This is gaslighting.

When I asked what do I do if I break a leg, I was told to go to the ER. If it isn't accessible, go home, contact the hospital, explain, ask for accommodation, and then try again in three weeks. As if anyone has THREE WEEKS notice of an emergency!5. Toxic positivity, inspiration porn, and gaslighting is rampant in the advocacy side of my local CIL. That any discrimination boils down to our perception of the discrimination and we have to choose how we feel about it, with the right answer being to care less about the discrimination. This solves nothing. And it is only happening in the advocacy side of things. Again, the educational side of our CIL understands how damaging this gaslighting is and works to learn and educate, yet the damage is being done by the other side of their own coin. 6. There is no 'other' category. If what the CIL normally does doesn't help in my situation, then that's it, there is no other mechanism to escalate. When I tried to talk to the CEO, I was shoved back down to an employee who gaslights me. I get that we use protocols because most people fall neatly into those categories, but there MUST be a protocol for those whose needs aren't met by the 'typical' methods. Everything about the structure of CILs appears to be based in accepting the status quo and working within the broken system. There seems to be no structure for reporting emerging disabilities like mine so that the systems can be modified and changed to reflect the reality of the disabled at the local level. Our voices are critical to full inclusion, and yet they are being squandered by the local-level CILs.

Peer support seems to be underfunded and de-emphasized when it comes to funding through State funds - competing for dollars with community mental health and medical models. This is frustrating as many DD and post injury groups do not fit the CMH guidelines for service and medical model will discharge a person from further helps once short-term goals/benchmarks have been met.

We need to know what resources already exist and what are needed. What coalitions or committees are meeting in the community? Are there certain functional needs that keep coming up in a community? Are there community members, businesses, churches, etc. that will assist with rural planning for people with disabilities?

it’s important to know that social support is necessary. that a safe home is needed if someone is going to be a working part of society. we need ready access to medications (without my medicine my PTSD is debilitating to a point that i see all men as evil rapists and i’d rather die then be touched or seen).

The serious lack of outreach. Nothing coming out of MDHHS/CMH or state advocacy groups directly related to meeting the needs of those more severely involved - those who can't walk or talk or have greater DD.

They do such great work! Kalamazoo Community Education team does great work.

Maybe more about how to work with caregivers if you live in the community

I am in a local women's support group for those with disabilities but I am lonely.

When a desk or whatever is changed, to see that it works for everyone.

I think we should shift focus on Interdependence Living. would that be a possibility? This would not be similar to Codependency

What should be done as accountability for public servants (such as law enforcement, judges, jails, government entities) that fail us with disabilities in access, decorum, disrespect, and denial of services. How do people feel they have a say in identifying and proving accountability? As of now it feels like there is no clear/concise way for someone to have their complaints heard and then action taken.

Nothing specific comes to mind that I haven't already mentioned above.

Independent Living is overrated! It is lonely and isolating for those unable to get out of the house. Many seniors have no family and few supportive friends due to isolation. Commercial senior living facilities give notoriously poor care with untrained and underpaid caregivers. Since they are allowed to call themselves “independent living” even though they provide a la carte personal care at extra expense, they are unlicensed and unregulated. Healthy meals and social activities are a fallacy. All this at astronomical costs -$5,000/month and up! There needs to be another, innovative solution for living, and it is critical, not only for the poor but for middleclass. Please contact me for more info. 231-313-8866.

I am lonely. I am a happy person who is able to sit and drink coffee and my caregivers are good. But I want to be able to go somewhere like school was - Lincoln to participate with my peers.

There should be college certifications for direct care workers.

There are not enough activities for adults who are cognitively impaired. Bite my tongue but some low producting folks should get subminimum wage. They do not care about the money they want to got to "work" and visit their friends like the rest of us.