

GCDD 5 Year Plan Providers Report

Report from research in Minnesota







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Background

The Minnesota Governor's Council on Developmental Disabilities (GCDD) is a public entity, a division of the Minnesota Department of Administration. The Council was created by Executive Order under Governor Wendell Anderson's administration in 1971 under provisions of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) (P.L. 106-402). The DD Act sets out the Council's purpose, the composition of its membership, and responsibilities, including the development of a five year state plan.

Presently, the GCDD has repeated the Quality of Life Assessment Survey (QOLAS), which was initially conducted in 2000, and repeated in 2005 and 2010. The findings will be used as input for the next 5-Year State Plan for federal fiscal years 2017 - 2021.

Research Objectives

Information was gathered from providers of services to individuals with developmental disabilities (persons who work for organizations that provide these services) regarding current opinions on federally defined areas of emphasis related to: employment, self advocacy, housing, education, recreation, quality assurance, early intervention, health and childcare.

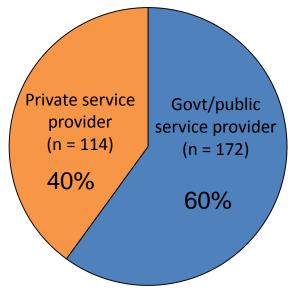


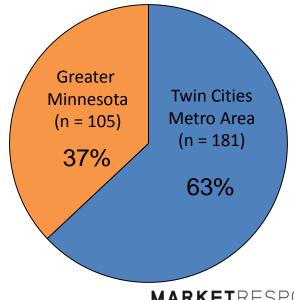
Methodology

Many groups and organizations were identified to get a cross cut of professional and provider groups. This outreach meant contacting and working with many groups and individuals.

Respondent Profiles: A total of 286 providers participated in the online survey.

Open-ended question responses were categorized by themes within each topic.

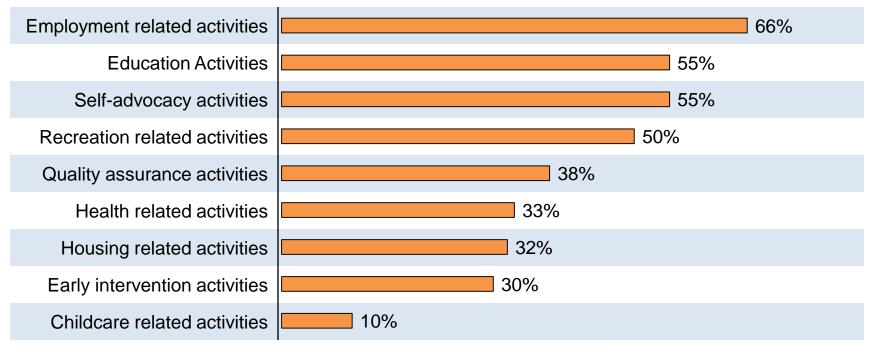






Respondent Profiles

Relevant areas of emphasis of providers working with individuals with developmental disabilities and their families:





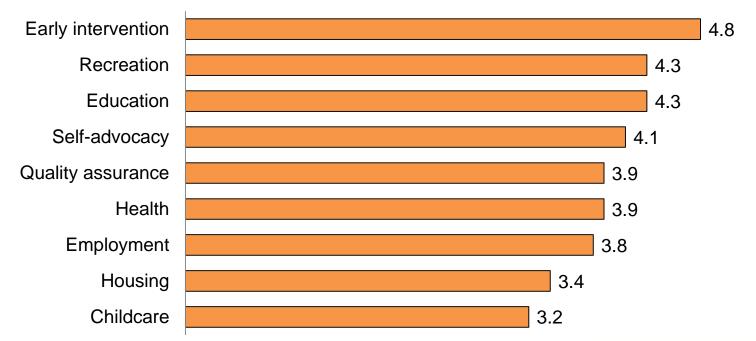
Executive Summary



How would you rate the quality of (area) for individuals with developmental disabilities?

Mean rating of quality in the following areas:

Poor			Satisfactory			Excellent
1	2	3	4	5	6	7

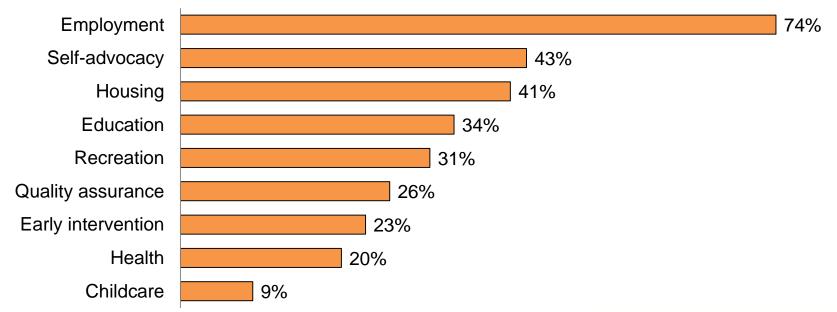




Top priorities for improvements over the next five years

Employment related activities was selected as the lead topic for improvement. Three quarters of respondents chose it as a top three priority.

What are your top THREE priorities for improvements over the next five years?





Detailed Analysis of Open Ended Questions

- Employment
- Self-advocacy
- Housing
- Education
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What is working well in **employment related activities**?

Focus on strengths of people with developmental disabilities to figure out how they can be productive and contributing members of the work force

Businesses that employ adults with disabilities find a great solution to finding dependable workers that will stay around a while. They find workers that are happy to be there and be given a chance.

Providers are working well with individuals to identify their skills and to further their skills. Jobs are being carved out to meet the individual's skills, abilities, physical abilities, etc.

Collaboration among the team to find the best job fit. Employers are more willing to carve jobs.

Case Managers are finally becoming more willing to look at Supported Employment; We are finding jobs albeit during weekends and evenings that fit individuals interests and skill set.



What is working well in **employment related activities**?

On the job assistance

Employers being flexible for job coaches to assist the employee.

We have several community providers who can provide ongoing job support for people once they have a job secured.

Consumers are offered a choice of center based or community employment or a combination of both. Significant strides have been made getting individuals into community employment opportunities that meet their unique needs, whether that be supported, competitive or some version in between.

Supported employment efforts, job-coaching, mentoring.

Through supported employment, many individuals are finding community jobs at competitive wages.

Having community employment jobs with job coaches on the premises. This helps bridge the gap for all individuals to hold a job and earn an income.



What is working well in employment related activities?

Community based employment opportunities that are supported seem to be working

We have had a regular amount of contract work for our individuals. There have been multiple leads for community based employment and we have been able to give that opportunity to some.

Individuals are able and willing to find employment in the community. Many have a support team that help with ensuring that progress is being made on the individual's side of things.



What is working well in **employment related activities**?

A stronger economy means more opportunity

Strong economy means more opportunities for people with disabilities to work.

Employment can be found without additional training because the unemployment rate is so low.

The number of jobs available is high. Therefore, the chances for individuals with developmental disabilities to obtain community competitive employment is higher than national average.

Employment increases levels of IPSII

Individuals are getting out. It is a social setting in the very least. For some DD individuals with high skill levels, it is a means of self determination, using talents and getting some reimbursement.

Sub-minimum wage certificates. They allow people that would never be able to get a community job (working at 15% of standard) to become so much more integrated! REAL choice for everyone, not demanding that everyone (even the most severely developmentally delayed) be looking for community-type jobs.



What is working well in **employment related activities**?

There is more choice, whether to work or not and what type of work

That the people I support have the OPTION to work or participate in recreational and skill building activities. They are not forced to work.

Many providers are offering support for competitive, community-based job searches, and moving beyond a one-size-fits-all approach.

I believe that what is working well is the multitude of work options for people with disabilities (incenter, independent/enclave community based, piece rate, reduced minimum wage certificates, etc.), which allows for everyone to have access to work, regardless of how profound their disability may be. I also think that there are strong organizations and staff who are dedicated to helping persons with disabilities succeed in their career goals.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **employment related activities**?

Employers need to be educated on the benefits of hiring people with developmental disabilities.

We cannot push for more community employment without putting resources towards developing these programs. We need to continue to educate employers, and provide good training across the county and state staff, to ensure we are all moving in the same direction.

Educating prospective employers and formulating good networks is key. If employers know and understand support roles and have additional resources available they are more likely to be a long-term employer.

Tax incentives could help employers to hire more people with developmental disabilities.

Tax breaks to employers will provide more incentives to hire people with developmental disabilities.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **employment related activities**?

Preparing for employment opportunities needs to start at a young age.

We need to start earlier in preparing for employment, with experiences in the community. We need to start as early as middle school and connect students with volunteer opportunities that build skills and networks, and can be leveraged in a job search. When students graduate from high school or a transition program, they often do no have very many marketable skills because they have not received adequate preparation. They also have a hard time understanding expectations of participation in the workforce. We need to promote self direction, and provide quality guidance and counseling in the process, so that people are pursuing jobs that match their background and help them to grow and progress.

Job classes and coaching

Providing more classes and on the job coaching. Also, more assistance to get into a job because passing an interview is challenging, even though the person might be the best for that job.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **employment related activities**?

Transportation can be a barrier to employment

I think what hinders people with developmental disabilities in the metro area is transportation. Many take the bus, but there isn't always a bus to a job they may want to do.

Individuals with developmental disabilities need extra support in caregiving and transportation. I have many individuals who are wanting employment, but have transportation issues and cannot rely on the transit system to get them to their employment site on time. Other individuals have difficulties with PCA reliability and cannot get to their prior appointments on time.

Access to public transportation and access to affordable housing. When these pieces are not in place, obtaining and keeping employment is much more difficult.

Opportunities for employment in rural areas are hard to come by

It is hard to find programs for employment in more rural areas of MN as opposed to the cities. The types of programs available are also limited.



Detailed Analysis of Open Ended Questions

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What is working well in self advocacy activities?

Schools are creating programs and recognizing the importance of self-advocacy skills

In schools there is an avenue to provide appropriate communication options for people with developmental disabilities.

Schools have really begun to recognize and focus on this as an important need for students even younger than ever.

It is a part of most classes for students with developmental disabilities.

Self-advocacy is a focus area for students in special education from ninth grade to graduation.

Students are participating in training activities at school, and are learning self advocacy skills in a coordinated manner. There are a limited number of community agencies available to work on self-advocacy. These agencies do a great job in providing activities.



What is working well in self advocacy activities?

Self-Advocacy groups are building leaders

The goal is always to help clients become self-advocates. This goal is throughout every agency with every client of every skill level.

Self-advocate leadership training programs like Partners in Policymaking and On Eagles Wings.

Organizations such as Arc Greater Twin Cities, Arc of MN, DSAMN, and PACER are making a real impact.

There are a number of self-advocacy activities out there that are officially recognized. Many more individuals consider themselves leaders and active members within self-advocacy activities such as voting, legislative efforts, presentations, etc. Many have experienced personal and group empowerment.

There are non-profits and programs that do well in preparing and training community advocates, among those with ID/DD. MN Governor's Council on DD's PIP is a model training program, as is work by the Arc, ICI, and ACT. Improvements are still needed internally in some of these programs regarding attitudinal barriers, and segregation of people on some of these committees, but overall most of these programs help build real leaders.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **self advocacy activities**?

Self-Advocacy needs the ear of the government

Increase contact with local elected political officials so that they are aware of the needs and wants of people with disabilities and can impact legislation as it relates to this.

Not enough funding available to support self advocate activities. Also, self advocates need to be at the table with all government agencies that make policies that impact people with disabilities.

We need more legal resources. Violence against people with disabilities is very high. The Arc United States has some information on their website about this. It is a topic that needs more attention.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **self advocacy activities**?

Begin self-advocacy training at earlier ages

Schools need to start younger. Parents need to be part of the process and education needs to expand with people who are more in their 30's 40's etc.

Emphasis within schools to ensure that people with disabilities are learning self-advocacy early and regularly. Starting in elementary school, I believe every IEP should have a self-advocacy related goal, and that it should be continued throughout their education.

More opportunities for students to self-advocate in secondary education (a supported environment) so that they are prepared when they go to post-secondary education and/or into the work force.

This is an area that needs to be started in school - at a young age or preschool. You can tell when an individual has had encouragement during their younger years vs someone who has entered adulthood with limited access to society. When a person gets to be an adult they are set in their ways, scared that they will say the wrong thing or get teased for not presenting well. Individuals attend programs when available but still highly rely on their caregivers for help and protection.



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What is working well in housing related activities?

Resources available for those who want to live in a group home

For individuals who choose to live in group homes, generally placement is available. Please note that few individuals with intellectual and developmental disabilities want to live in group homes.

Regulations favor the state to drag their feet on group home options

More attention is being given to non-group options. CMS regulations should help, but implementation timelines give states a lot of time to drag their feet.

The push is to have people live in their own apartments with services.

High quality foster care providers are out there

There are some excellent corporate foster care providers out there.



What is working well in housing related activities?

Schools can be a useful resource in identifying housing options in the community

Some schools have social workers that can help connect students and families with community agencies that help with housing.

Increased awareness and some availability for Independent living options

There is a push to have people live in their own apartments with services.

Many providers are now offering opportunities for persons to live in their own apartment with 24 hour assistance. These supported apartment programs are great when you can get in one and afford the rent.

Increase in funding in this area is really helpful

MSA is helping clients with developmental disabilities (if they qualify) make their rental payments in GRH apartments. This funding source has made it possible for clients to have more funds to pay other living expenses.

There are so many more options to help clients find the best housing option that suits their needs while being able to grow in their independence.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **housing related activities**?

Access to housing and services is very different in Greater Minnesota

We do not all live in the cities. We do not all have the access to everything that is in the cities. The State needs to remember that there is a greater Minnesota. Although the population may be in the cities the whole State has people with disabilities and not all the rules fit to greater MN. It is impossible to integrate someone with DD into the community when there is no housing available. There are no services available in certain areas and people have to drive many miles to get those services.

There are not a lot of choices (availability) in central/northern Minnesota. Vulnerable people are taken advantage of or get involved with the wrong crowds - providers are not able to hire enough staff to support them in independence which causes them to fail, become harmed or unsafe and increases costs when crisis arise.

In the rural community, we are in need of housing for clients who can live in an apartment but need 24 hour support services on the premise.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **housing related activities**?

Students with developmental disabilities need more options-this is a safety issue as well

There are not a lot of options for our students in our community; not enough affordable housing options that are safe for students with developmental disabilities.

We need more opportunities for group homes for students with disabilities that are not just developmental cognitive disabilities.

Staffing is a real problem

Staffing with regards to group homes, is awful right now. The staffing shortage leads to problems with the home not having enough supervision and can lead to issues with the clients. The turnover in this field is far too high.

The staffing challenge is significant and real. We do provide excellent services, but our long-term staff are working a lot of hours because of our staffing turnover. There are a lot of choices for people in today's economy and turnover causes financial hardship as well as emotional and real hardship to clients. Policy makers cannot underestimate the impact that staffing has on our programs. We need to put the breaks on policy changes and receive assistance with staffing. Funding is not the only answer; but it is one; Research Report 12/15/2015

MARKETRESPONSE



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **housing related activities**?

Funding in all areas of providing housing for the DD is really needed

There is currently a dearth of funding for individuals that desire affordable housing other than in a licensed, group setting.

Subsidized/affordable rent is extremely difficult to come by especially given the market we're experiencing currently. If a person's support benefits would allow them to pay market rent for a standard living space, they would truly be afforded the choice and independence many of these programs were created to provide.

We need more providers with the expertise needed to help families find housing for their adult with a disability, match to roommates, budget planning, etc. This way, we can avoid group home placement.

Individualized housing options (IHO) have not been supported with funding. Funding for options like adult foster care is being decreased for many dramatically (again, we are considering the option of divesting our organization of these services due to unsustainable budget issues related to decreased revenue). Yet at the same time, other successful alternatives have not been provided and/or funded to my knowledge.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **housing related activities**?

Ending the moratorium on group homes

The Moratorium on group homes for people on the developmental disabilities waiver and/or with developmental disabilities NEEDS TO END!!!! At this time, people who want to live more independently, cannot because they need more support and supervision. To think that everyone can live in an apartment without having staffing there at all times is foolish. Some people, especially those who are medically fragile or who have high care needs are simply not able to be left alone for any period of time.

Remove the cap on development of new beds/homes for individuals with developmental disabilities. There is always going to be a need for SLS homes, and there are people who could benefit from getting into a home.

There needs to be more funding, especially for IHO. Right now people have a lot of options but only if they or their family can afford it. The cap on Group home beds needs to go, it is a barrier to many clients getting the services they desire, especially people new to the waiver system.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **housing related activities**?

Teamwork/Accountability between providers, families, social workers and counties

Guardians and family members need to be better educated and invested in the person's life. They need to come to meetings, engage themselves, and do the necessary paperwork. They need to follow policies and there needs to be accountability on their part. Also, counties and social workers need to be held accountable and knowledgeable and do the necessary paperwork. It shouldn't be just the providers who are responsible and accountable and subject to non compliance. All the wording keeps talking about TEAMS and so far, that doesn't always happen.



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What is working well in **education activities**?

Knowledgeable staff, providing high quality education

Staff building relationships with clients and helping them through decisions.

Students are receiving quality special education services in schools and being integrated with their peers.

We have strong educational programs for our students. It gets more difficult to include the students with their general education peers in classes at the high school level.

Educational professionals are engaging in learning about their students' disabilities to best help them. Through the use of systematic processes, we are meeting needs.

Increased levels of inclusion in the classroom

We have SOME excellent educators who are trained in both general education and special education, who adequately treat all children as equals and are skilled in accommodating children in the same classroom.

Inclusion of students is growing in all aspects of school programming.

Recognition of the need for inclusion. Emerging recognition of using evidence based practices.



What is working well in **education activities**?

Employment and life skills related

Many people with disabilities have the option of a transition period between finishing high school and beginning a work program. I believe this helps to provide some additional helpful education services that prepare a person for the next step in their lives.

Depending on the clients, we teach life skills, such as cleaning, handling their own money, shopping on their own.

The educational planning and long term goals for those with developmental disabilities.

For some, resource needs are being met

We are provided focused support for students with a wide variety of needs from mild to unique students with complex requirements.

We were able to secure grant funding to obtain a Smartboard and have adaptive equipment to allow those with limited mobility to be able to access the screen and interact with educational apps.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Need for life skills education/training, enrichment programs

Access to appropriate curriculum for all levels, availability to use technology at all times, not shared times. Increase of adults to model, guide and take students out in the community to practice social skills, etc.

The community needs to be educated and services need to be provided in an inclusive way.

Need more enrichment opportunities/programs for after school and during the summer. Not all students qualify for Extended School Year and are not able to access other educational and/or enrichment programs due to individual and program barriers.

Smaller communities struggle to find a variety of environments for students to complete on the job training/ transition activities. This is important for students who will continue to live and work in the area.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Need for increased focus on transition services

Transition services needs to be improved greatly. No client that is severe is going to be able to work completely independent without some staff assistance of some sort. The transitional services that can be provided need to be looked at and the requirements that a person needs to jump through in order to get those services is ridiculous to say the least. There are day programs out there and they can provide services; but the communication between schools and day programs is lacking and most teachers aren't aware of what is actually out there for the kids. More education and less restrictions on what and who can help students transitioning out of high school is a much needed improvement area.

Transition programs need to be aligned with the adult service providers.. After all IDEA says transition should start at age 14.

Prepare them earlier for the next phase of adult life. Many move into the adult services world with unrealistic expectations regarding service supports and options.

With some of our more challenging students, we need to have more options for transition activities to get them integrated into community and work sites.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Continued Educational Services for Adults are needed

Day Treatment and Training for adults has no educational component. Excluding individuals with intellectual and developmental disabilities from life long learning opportunities.

I think these types of services still need to be improved upon as Individuals with Developmental Disabilities become older. Employment, Housing, Health Care, and Daily Living are all critical areas that continue to need attention.

Teaching how to be an adult and be independent.

More partnership with state and county once students turn 18. Decisions made on what makes the most sense for the student's future instead of who is paying the bill.

Jobs need to be found that are more integrated and in the community, through the schools. For the most part, if kids have jobs, it is a 'school' job, and they cannot take the job with them when they graduate. Schools also need to work better with the human service agencies and communities



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Providing the right services, in the right way for minorities and multicultural families needs to improvement

Still a segregated system. No real discussion of how to embed services in the generalized setting. time to have real reform.

Real team work with multicultural families.

Birth-k12 and adult education services need to address disparities between black and white individuals. Birth-k12 kids are identified as being disabled but sometimes not for the correct disability. For example African-American kids are labeled emotional behavioral disabled when often they have a neurobiological disability.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Budget cuts are a continued threat. Increased funding is needed

Funding continues to go down, this decreases ratios and does not assist our clients in any way.

funding - funding -funding: We cannot expand activities or increase inclusion without dollars to support the activity or the people to support the individuals in activities.

Additional funding for additional staff. Our clients learn best when they have direct human involvement at a richer staff to client ratio.

With limited funding we are not able to purchase the adaptive games and equipment that would benefit the population we serve.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Need for more special education staff to support integration, inclusion efforts

A focus on best practices within inclusive programs, training, staff development of all teachers and paraprofessionals. Access to academics and true engagement in general education takes specific work. There are too few districts specifically focusing on the possibilities of people with disabilities within general education classrooms and settings. It is not second nature yet - it is not well understood, but the benefits are clear.

Providing teaching assistants within the classroom would benefit not only special education students but the entire student body.

Integration in general education classrooms needs to be focused on both the social benefits and learning objectives for students with complex needs.

Full integration can be very difficult based on bias and beliefs.

More integrated settings, less emphasis on special schools



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **education activities**?

Too much paper work

The qualification process and ongoing paperwork for Special Education services is cumbersome and time consuming.

Reducing paperwork so people can spend their focus on KIDS!

Too much testing required of children with learning disabilities.



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What is working well in recreation related activities?

Opportunity is there

MN has a variety of recreational activities that are integrated....bowling leagues, golf, swimming, fishing, skiing, concerts, theaters, museums, parks.

Most adult foster homes provide their clients many recreational activities in the community as well as in the home on a consistent basis.

There are so many options for our individuals to attend activities geared towards their abilities, but there are also community activities out there where individuals with developmental disabilities are more accepted now.

There are many groups geared towards people with disabilities, many of which are led by people with disabilities. There are also many places that offer reduced membership/entrance fees to make them more accessible to people with disabilities who often have a very fixed (or limited) income and who also may require staff to go with them.

Most providers do a fantastic job providing an array of experiences, which promote community inclusion, fitness and social/physical exploration.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **recreation related activities**?

Travel expenses and transportation to recreation activities is an issue

Northern St. Louis County Case Managers are now requiring that we as the provider share in the cost of hotel expenses when we take individuals on an activity. Ironically at the same time, the County allows some providers to stand by their 'no overnight' activities policies, which robs individuals of any overnight trips.

There is a greater MN. We do not have access to city buses, taxis, trains etc. We have our own personal vehicles and if we are lucky the organization that we work for has a vehicle to use....but that is rare. So traveling for recreational activities is a challenge and is very expensive especially when things are usually held in bigger towns and again you have to drive many miles to get there.

TRANSPORTATION to all types of activities 7 days a week, including evening hours. Recreational opportunities exist, but without public transportation to get them there, they are not able to participate.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **recreation related activities**?

Funding for staffing is needed for people to be able to participate

Lack of staff as we cannot pay enough to be competitive. NEED cost of living raises for the staff who work with people with disabilities.

Adult foster homes need staff with recreational background and funding to support recreational activities.

For those living in an independent setting who may need companion services, these services are difficult to find people interested in working them. The hours of service are typically short and are paid at a low rate making it difficult to retain an employee.

Financial resources are not readily available to make these thoughtful integration opportunities regularly available to each client requesting services. More funding needs to be made available for provider wages, so that retention of staff doesn't inhibit services delivered.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **recreation related activities**?

Community support and accommodation can play a bigger role

Community organizations could partner more with the schools so that students' families can be aware of outside of the district opportunities.

Need to continue going out in the community to change people's perspective to a positive one on people with disabilities.

Ensure that when the city, school or community center is offering programs that they are ready and willing to make the needed accommodations to ensure it is a pleasant event for the participant with the disability.



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What is working well in quality assurance activities?

Personal growth and esteem are building

Individualized plans and choice, work towards quality

Making sure they know their own worth and how very important they know they are to the community

When good people are in charge, people grow.

People with disabilities are participating in intergraded activities more frequently.

They are assured of safe, supported living.



What is working well in quality assurance activities?

Oversite and monitoring services are much improved

There are some wonderful quality assurance tools that have been created and being used in some places but not statewide.

There are many programs and agencies that you can get assistance with monitoring the well-being of those with developmental disabilities.

County Case management is excellent. We have a fabulous, experienced, committed case manager, who makes sure all the t's are crossed and i's dotted.

County Based Services are monitoring waiver service Individual Service Plans.

In schools, we hold ourselves to high standards in programming. We are also monitored and provided direction by local, state, and federal mandates.

The Olmstead plan gives us hope that things will be re-designed to be more person-centered and family-centered, so that we can design supports and systems to be nimble and flexible according to each person's goals and strengths and needs of supports.



What is working well in quality assurance activities?

Aligning with other organizations is a positive

There are some great things such as People First, Arc and other agencies that provide seminars, etc.

Self Advocates of Minnesota, People First and other self-advocacy groups

Decisions to partner with groups such as the Arc Housing Access Program that has shown to produce a positive outcome.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **quality assurance activities**?

There are many different quality assurance activities going on in the state, but it does not seem like anyone knows the overall plan and efforts are not coordinated.

There needs to be a comprehensive plan to have quality assurance activities to monitor the success and challenges of services and supports. Persons with disabilities need to be front and center in terms of the design, development, monitoring, and evaluating of the activities. There needs to be a clear understanding by all to what informed choice is and options available.

There is just too much going on at one time. It is the perfect storm for providers, between assuring quality with 245D, understanding the changes with Disability Waiver Rates System and the regional rate variance, the waiver amendments, the transition plan, the Olmstead plan.... It is so overwhelming. There is not a plan to roll these things out; it is all coming at once, hence compromising quality.

The left hand does not know what the right hand is doing at the State or in DHS. No one at DHS seems to have any clue as to what life is like for people with developmental disabilities. First of all, get a commissioner that has some life experience with people with disabilities. Secondly, have panels with 'experts' who either have children with developmental disabilities or have worked the front lines for people with developmental disabilities. Right now, the plans that are being made are not realistic or functional for people with developmental disabilities.

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Service Providers -- Quality Assurance Activities

What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **quality assurance activities**?

Abundance of paperwork takes time from the people in need

More emphasis on technical assistance regarding quality of programs rather than paperwork. The Federal Government could get rid of the CRDC survey they require annually given that data is already housed at the state level. Districts are doing duplicate work that takes away from time improving programs

The amount of bureaucracy and regulation siphons resources which could better be used for program development and implementation for those who need it most. It is a counterproductive to create legislation and regulation that make funding less available due to the need for organizations to focus so heavily on compliance.

CLEAR direction and forms and training to make it easier for providers to have the tools to train staff and document quality assurance.



Detailed Analysis of Open Ended Questions

- Employment
- Self-advocacy
- Housing
- Education
- Recreation
- Quality Assurance
- Early Intervention
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Service Providers -- Early Intervention Activities

What is working well in early intervention activities?

Strength in early identification, awareness of need for services

Child find is strong in our area of the state. We have good programming for early childhood students and include them in preschool settings as much as possible.

We have amazing hard working staff focused on making progress for our early learners. The state's help has also been beneficial to our programs.

I think that public schools and other public agencies have become much more knowledgeable and proficient in providing Early Intervention Services over the years. Certainly much better than I believe it has ever been. Also, professional educators and other agency staff are much more informed about Early Intervention Assessments and appropriate opportunities for young children.

Awareness and access in WHITE and upper income communities is strong.

Collaboration among teachers, speech therapists, occupational therapists, physical therapist, parents, and other professionals.

There has been increased focus on early intervention activities over the past year. This would include things like best practices for working with Somali families who have children with autism.



Service Providers -- Early Intervention Activities

What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to early intervention activities?

More funding and resources are needed

More money, more time given to each student and family, more resources on county assistance and services available.

Funding level does not allow us to provide the highest quality programming and often results in funding being diverted from other students.

There is a shortage of ECSE teachers and a shortage of college programming for that licensure.

MA parental fee is a huge barrier to middle class families, trying to access services under MA.

Make knowledge of resources more available so that everyone is able to access the same resources. I have heard of some families that were unaware of how or what services they could access or unsure of where to go to access these services. Present the question - and provide the guidance of why it is important for the child and then where to access that service.



Service Providers -- Early Intervention Activities

What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to early intervention activities?

Need for increased awareness and access to resources

We need the same access and awareness for people of color and for low income (rural and urban). We need open minded folks with strong cultural competencies for staff and providers.

More information about diversity and cultural issues so providers can team with the family and fulfill the needs of the child.

Transition services

I think that much more still needs to be done in the area of Transition Planning for Individuals with Disabilities. There are individuals who still don't see this as a priority, but it's critical.

More in-home services are needed

I wish we could have in-home therapeutic support for kids and families. When I started 25 years ago, this was an amazing support for families.

Home based therapy and help, provide more opportunities in various settings for families and kids to develop skills of independence.



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What is working well in health related activities?

Health related services are often being met for students with developmental disabilities

Critical care for individuals with intellectual and developmental through age 21.

Schools provide health related care at no charge to students (speech, OT, PT, nursing).

Students are getting access to quality, needed health care services.

Legislation expanded resources and services

Past legislative session included more resources for a wide variety of services. Now we need to implement them.

More families have insurance /access to healthcare thanks to MNSure opportunities.



What is working well in health related activities?

High quality physicians

Physicians take a very pro-active approach.

Most physicians and other health care professionals provide excellent services, especially in our rural area.

There are some good doctors out there who work well with our individuals with disabilities.

Supports are there to help understand and navigate the complexities of the health care system

Managed Care providers who help navigate the complicated health care world.



What is working well in health related activities?

There are providers that make sure all health related needs are being met for their clients

Access to care, especially in the metro is readily available. The variety of available benefit programs and the continued flexibility of them are providing an opportunity for people to create service packages to meet unique needs.

There is a new organization that will do home visits for persons too anxious to leave their homes.

When you can get a decent provider that will take the time and listen to the individual and care giver, that then works.

They have excellent health coverage. They need an advocate to help them get this excellent health coverage.

There is unlimited access to medical and dental care for the population we serve.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

Dental and mental care and reimbursements are lacking

Adequate dental care and mental health care resources are greatly lacking. This is due not only to a lack of adequately trained providers, but a lack of adequate insurance reimbursement to these providers so that they can sustain their practice and afford to see this population. Being ranked LAST in the nation for MA reimbursement is nothing to be proud of:

Access to dental care for individuals with challenging behavior and intellectual and developmental disabilities who require intubation.

There are no dental providers for people. People with severe disabilities have to wait 12-18 months to get general anesthesia to have cavities filled and dental work done. My own son has a cavity and needs wisdom teeth pulled under general. He has been on a waiting list and there are no openings.

Access to dental care is a big problem in our community for individuals with developmental disabilities, particularly because of the low MA reimbursement.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

Dental and mental care and reimbursements are lacking (continued)

Not enough dentist or mental health providers. Dental visits were limited to once a year, now has returned to twice a year. Actually, individuals on psychotropic medication should be seen every 4 months - this preventative would save the state more money than when extensive procedures have to be done due to lack of care. The same for mental health providers - it takes months to get into a provider and when a crisis comes, the individuals are transported to another hospital where their provider is not located nor does the hospital talk to the individual's psychiatrist about the person's care plan.

Dental services: Let the dentists get paid to take on the folks we support. At this point, they are segregated and really only have one choice of providers, because no other dental agencies will accept more MA patients.

People need to have access to dentists and psychiatrists. At this time, it is very difficult to get, find and keep a dentist. That is primarily because those specialties are not reimbursed for the care they provide, so there is no incentive to accept people who have MA or Medicare.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

Minorities struggle to get access to healthcare information and services

Lack of basic access to healthcare system for African-American individuals with intellectual and developmental disabilities.

Many people who lack resources and who come from ethnic and underrepresented racial groups are not able to know of or access supports and services that are culturally competent and they do not as often experience hopeful attitudes or positive supports from the people who provide them care. It is substandard and not culturally competent care right now.

People with developmental disabilities are not taken seriously by all physicians

There are still a few physicians with negative attitudes and lack of value of disabled individuals. This forces us to be fierce advocates.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

There is a need for expanded care from healthcare providers to meet the complex needs of people with developmental disabilities

We need more dentists, Psychologists and Psychiatrists who can accept people with Medical Assistance, who specialize in working with individuals with a developmental disability diagnosis as well as person with a dual diagnosis of IDD and MH.

There needs to be an increase in treatment programs for persons with an IDD diagnosis and a sex offending history.

There needs to be an increase in options of having doctors provide in home medical care for individuals with aging and mobility issues.

Affordable housing leads to increased overall health related outcomes

I would like to see more financial investment in safe, affordable housing. It's hard to focus on your mental health recovery if you're living in a shelter or couch hopping with friends.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

Health care providers need to be educated on how to serve the population of people with developmental disabilities

Better education for health care providers regarding providing services for people with developmental disabilities.

Education to doctors/clinics on working with those with disabilities also needs to be improved. I have been to my fair share of appointments where clients are ignored and they only talk to staff.

Dental care is lacking. Dental students should all be taking courses on how to serve people with disabilities.

Healthcare professionals need more sensibility and listen to the community about real issues that people with disabilities and their families have.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

Many healthcare facilities are not accessible

NO CLINICS ARE WHEELCHAIR ACCESSIBLE. There are NO LIFTS FOR WEIGHING patients in wheelchairs and the rooms can barely accommodate a client in a wheelchair, their parent and the caregiver. People with disabilities cannot even get out of their wheelchairs onto a table like a regular non-disabled person.

Need for more community supported physical activities like adaptive sports

Health related activities need to be more accommodating for the physical challenges they may have. More adaptive sports and facilities, greater outreach within the community to not just promote the activities, but provide the transportation and support staff to participate in them.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

It is difficult to access quality healthcare related services for those living in rural areas

It would be good to have physician care services (such as Bluestone) available in the rural areas. Especially for those clients who are non-ambulatory and fragile. It is difficult to get them to doctor appointments in the cold winter. Also, we have the need for more specialists in the rural areas. Many clients with developmental disabilities need to travel a number of miles to access services such as neurologists, psychiatrists, etc.

There is a severe lack of qualified providers in outstate Minnesota. When a provider is identified it often results in extensive travel time for the recipient.

Transportation issues

Transportation is a challenge. Even with the options available, many individuals with disabilities continue to rely on their providers for transportation as the public options are difficult for them to arrange or are not efficient from a time standpoint.



What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to **health related activities**?

Education and services on how to access available health related services is needed

People need to be educated as to what is available. Advocates need to assist people through the complicated health bureaucracy.

The system itself is overly complicated, it would be nearly impossible for someone with a disability to navigate on their own without assistance.

More information or access to mental health services in the school environment.

TEFRA can be too expensive for those with a middle class income

The Tax Equity and Fiscal Responsibility Act (TEFRA) parental fee is a HUGE barrier for middle class families. Often the parental fee is too high to access TEFRA, meaning they are not getting necessary therapies, PCA services, waivered services, etc.



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Service Providers -- Childcare Related Activities

What is working well in childcare related activities?

Collaboration between providers results in a higher level of supports and inclusion for students with developmental disabilities.

Childcare centers are beginning to meet with us with greater regularity to collaborate. Our District's childcare program is wonderful at providing staffing and supports for children enrolled in their program.

Multiple agencies and program providers are working in a collaborative mode to expand our offerings and bring those with disabilities into the after-school program arena... for inclusion. Our collaborative work is to remove isolation of those with disabilities and strengthen inclusion of children and adults with disabilities in our everyday life.

Resources are available to those who are resourceful.

The programs that are out there, helping families with before and after school care are really awesome, just not enough of them.

There are resources out there to help, if one searches them out.



Service Providers -- Childcare Related Activities

What needs to be changed or improved so that people with developmental disabilities may be more independent, productive, self determined, integrated and included in the community with regards to childcare related activities?

The younger years of childcare seem to be more equipped to handle the needs of students with developmental disabilities, compared to middle school and high school age students.

Parents have difficulty finding appropriate care for children who are older than typical child care ages. I see this specifically as children enter middle school.

Sometimes when they are school age, they have those but kids and families still need support when they are in Middle School and High School, not just young.

There is a need for more funding and resources

Preschools may not have the support, knowledge or willingness to serve all children.

Children with significant behaviors (even very young children) are often not able to participate in child care settings.

Centers need to receive more support and funding in order to work effectively with these children and their families.

There need to be more child care providers/centers that can take kids with disabilities.

Working with diversity and cultural sensitivities. Need more staff training.

Quality staffing, having people that are knowledgeable and have the ability to work with those that have disabilities.



A Challenge from a service provider:

Work is still needed to remove the physical barriers to access sporting facilities and buildings. I would like to see a promotion that individuals with developmental disabilities have the ability to learn and overcome obstacles. Show a real life story of successful individuals with developmental disabilities and what steps they took to over come the obstacles in their way - the time line to success. Agencies that assisted in the process; the self assessment process to know what they wanted to do and how they developed their support system. Provide a real recipe for success and the process/steps to get there.



Thank you!



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