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project :: 1713

january 2006

GCDD 5-Year Plan Research Report Service Provider Survey

prepared for:

**Minnesota Governor's Council on
Developmental Disabilities**

prepared by:

marketresponseinternational

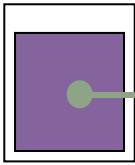
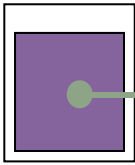


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**1::
executive
summary**



executive summary

This survey asked providers on services for individuals with developmental disabilities to provide input for the GCDD's 5-Year Plan. Respondents were asked to:

- provide their area of emphasis,
- rate their satisfaction with the various areas of emphasis,
- identify priority areas of emphasis, and
- provide opinions on what is, and what is not, working well in their areas of emphasis.

There is clearly room for improvement in the provision of services to individuals with developmental disabilities in the state of Minnesota. Only three of the nine areas of emphasis achieved satisfactory quality ratings.

Minnesota service providers identified the following three areas of emphasis as the top three priorities for improvement over the next five years:

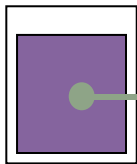
- Employment related activities
- Health related activities, and
- Self advocacy activities.

General themes across the areas of emphasis include:

- while awareness of issues confronting individuals with developmental disabilities is increasing, it could still be improved,
- recent funding cuts have impacted programs for individuals with developmental disabilities across all areas of emphasis,
- service providers of all types could improve their communication with one another and provide better coordination of services for individuals with developmental disabilities.

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**2::
project
overview**



project overview

Background

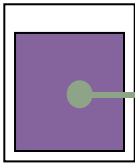
Under the Developmental Disabilities Assistance and Bill of Rights Act, each state was granted the authority to create a Council on Developmental Disabilities. For the past thirty-five years, the Minnesota Governor's Council on Developmental Disabilities (GCDD) has served as an advocate for people with developmental disabilities - people with the most severe disabilities who may require long term service and support (about 1.8% of the state population). With support from the GCDD this segment of the population strives to be "treated as people first".

The social model has redefined "disability" and has put responsibility on society to change its attitudes and practices to include persons with developmental disabilities, rather than changing this population to fit society. The GCDD's charter is to assure that individuals with developmental disabilities receive the necessary support to achieve increased independence, productivity, self determination, integration and inclusion (IPSII) in the community.

As part of this charter, the GCDD is required to develop a 5-year plan. In order to develop this plan, the GCDD is seeking to obtain input from providers of services to individuals with developmental disabilities. This is the first time GCDD has surveyed this population.

Research Objective

Our objective was for this survey was to obtain input for the 5-year plan from service providers. This research was conducted via an online survey.



project overview

Methodology

contacting respondents

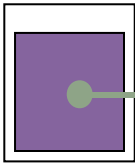
- :: GCDD provided MarketResponse with lists of providers of services to individuals with developmental disabilities -- including all organizations that receive GCDD funding . They were sent an e-mail invitation to complete the survey.
- :: The GCDD staff personally contacted 45 local self-advocacy groups and over 100 organizations, universities, schools, and listservs to notify people about the surveys. Several state agencies, including the Department of Human Services and the Ombudsman Office for Mental Health and Developmental Disabilities, placed a link to the surveys on their web sites.

survey format

- :: This survey was administered via Internet.
- :: 152 providers with various areas of emphasis completed the survey.

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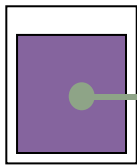
**3::
sample
profile**



project overview

Respondents were asked to select their areas emphasis in working with individuals with developmental disabilities and their families. The nine areas are defined as:

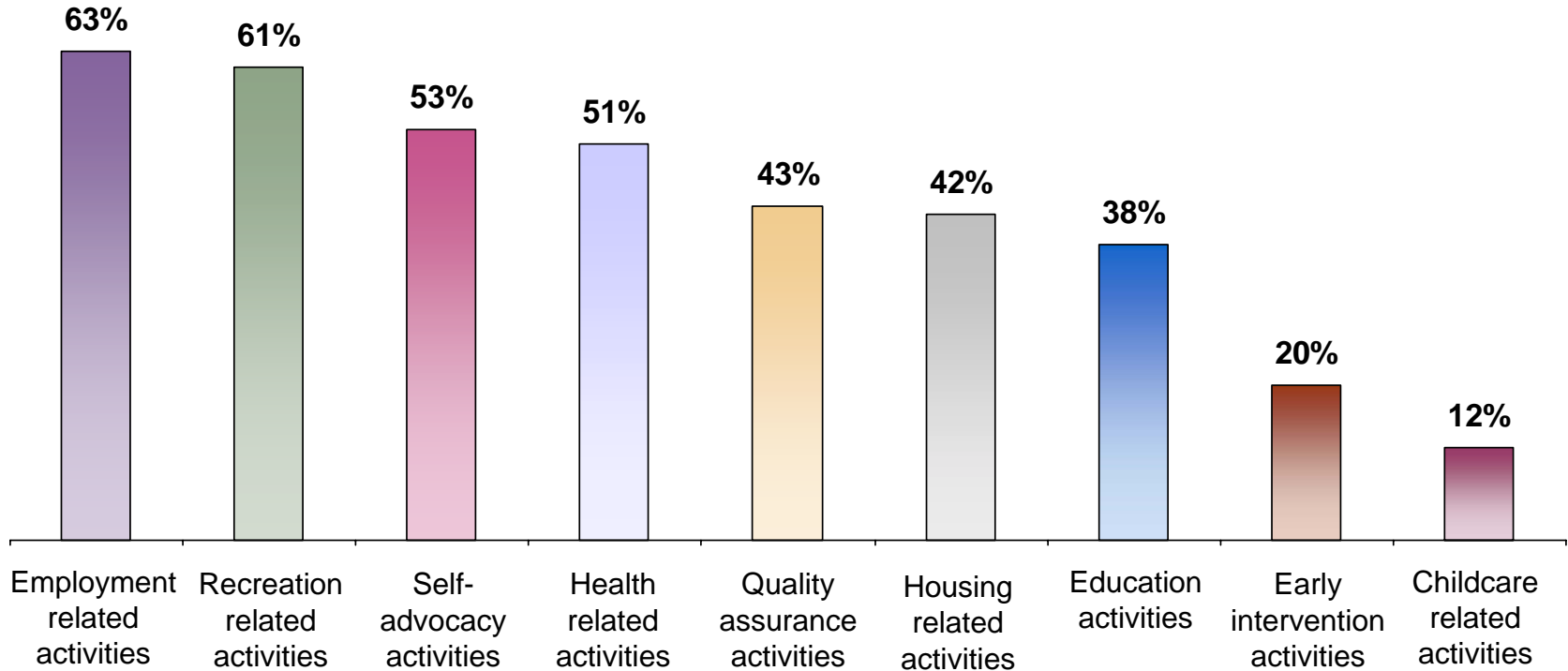
Employment related activities:	acquiring, retaining, or advancing paid employment
Recreation related activities:	providing access to and use of recreational, leisure, and social activities
Self-advocacy activities:	including self-advocacy and self determination
Health related activities:	providing access to and use of health, dental, mental health and other human and social services
Quality assurance activities:	monitoring of services, support and assistance and/or training in leadership
Housing related activities:	housing and housing support services including assistance in renting, owning or modifying an apartment or home
Education activities:	for children and adults
Early intervention activities:	birth to age 9
Childcare related activities:	including before school, after school and out-of-school services



sample profile – service provider emphasis

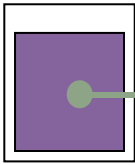
Areas of emphasis in working with individuals with developmental disabilities and their families:

n=152



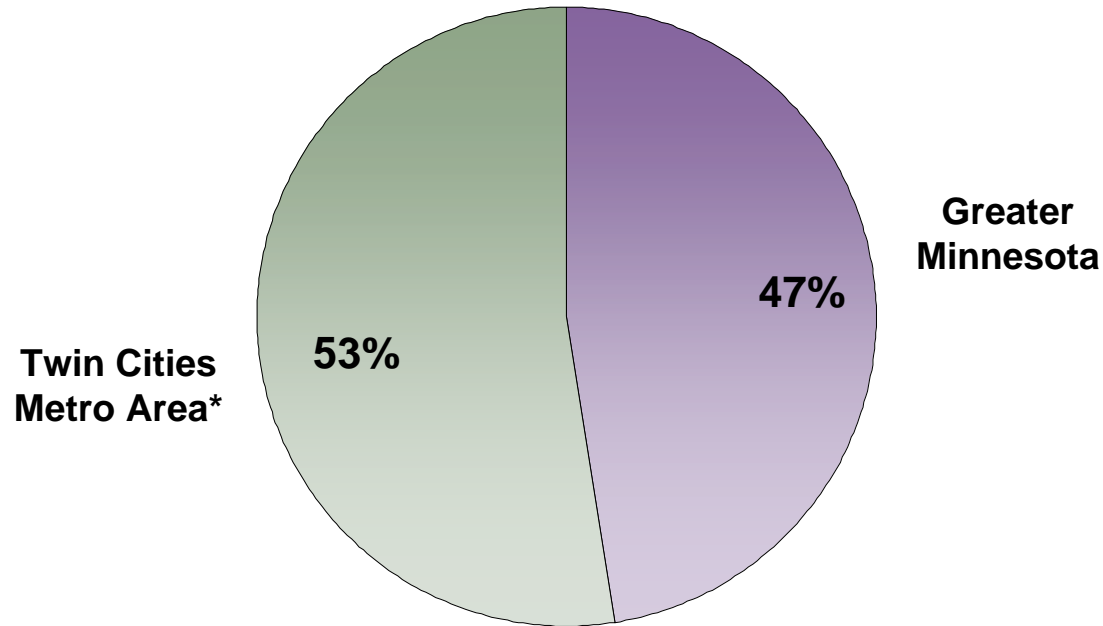
Note: Multiple responses allowed.

:: There were 152 service providers that responded to this survey. On average, providers selected 3.8 areas of emphasis.



sample profile – service provider location

Service Provider Zip Codes

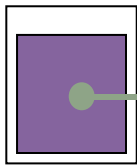


:: Respondents were limited to providers with Minnesota zip codes. There was strong representation from both the Twin Cities Metro Area and the rest of the state.

*The Twin Cities Metro Area is defined as the following seven counties: Anoka, Carver, Dakota, Hennepin, Ramsey, Scott, and Washington.

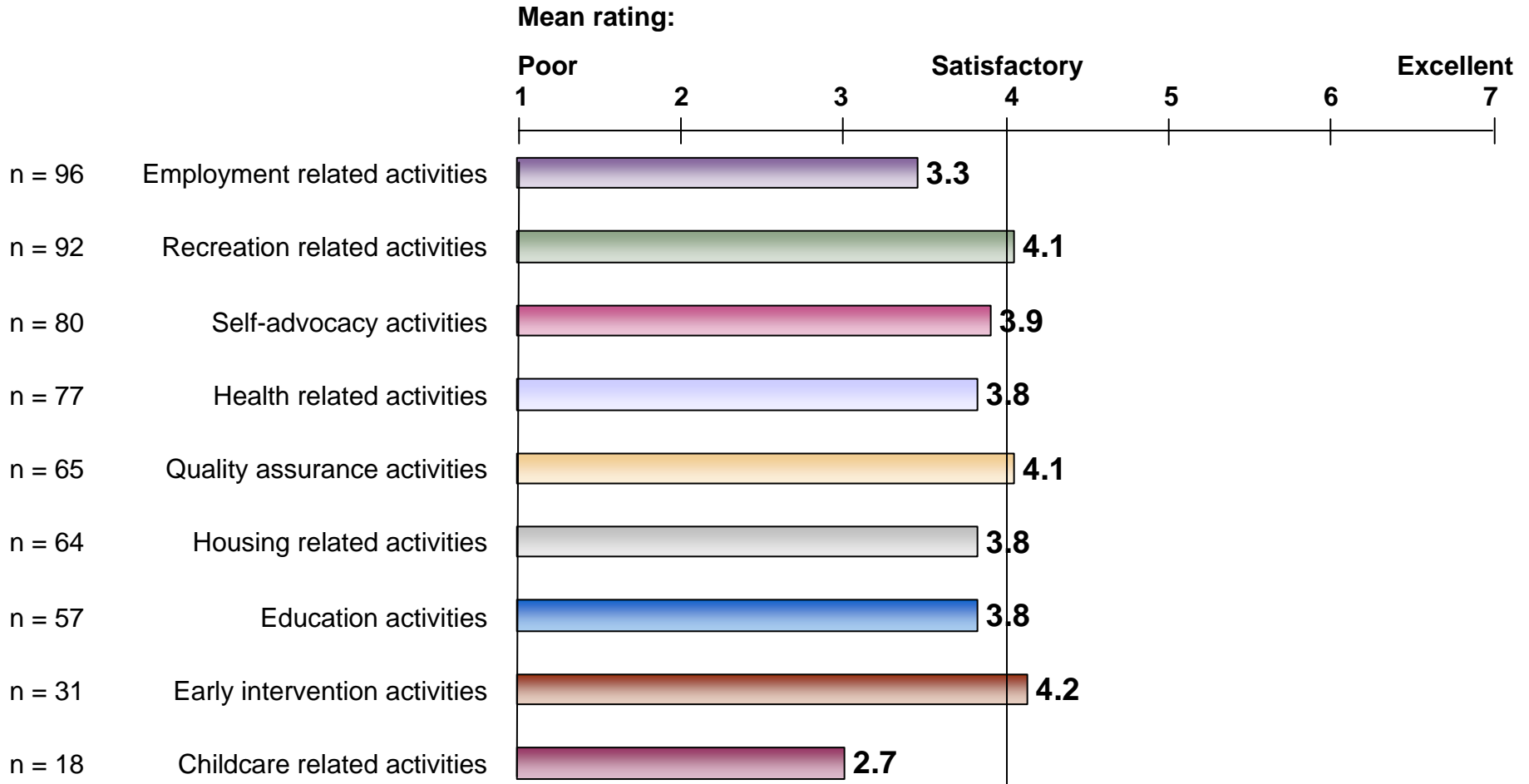
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**4::
provider
evaluations
of services**



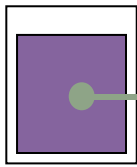
provider evaluations of services

Quality of activities and services for individuals with developmental disabilities in Minnesota:



:: Across the nine areas of emphasis, service providers rated six below satisfactory, with only Early Intervention, Quality Assurance, and Recreation rating above satisfactory.

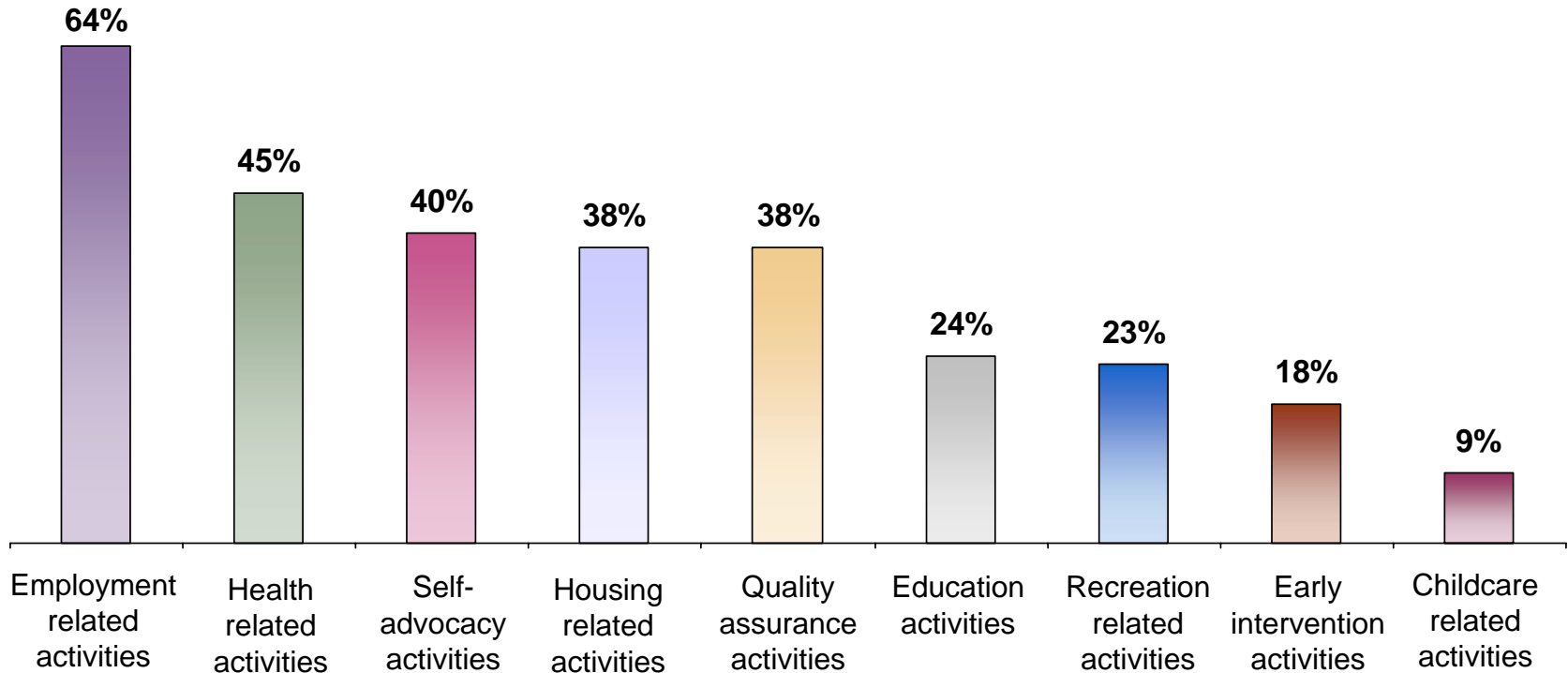
:: Childcare related activities was the lowest rated area of emphasis.



provider evaluations of services

Priorities for improvement over the next five years

n=152

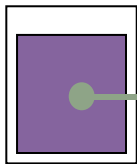


Note: Multiple responses allowed.

:: Respondents were asked to select their top three priorities for improvement over the next five years. Employment related activities rated significantly higher than the others, followed by health related and self-advocacy activities.

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**5::
focus on
employment
related
activities**



focus on employment related activities

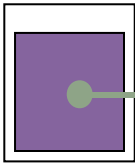
Respondents who reported an emphasis in employment related services were also asked to identify what was working well and what could use improvement in this area.

The most commonly identified areas that were working well were:

- :: Employers becoming more open to hiring individuals with developmental disabilities.
- :: More awareness of employment issues for individuals with developmental disabilities.
- :: Day programs are offering more work related activities and programs.

The most commonly identified areas for improvement were:

- :: Awareness and education of employers and community.
- :: Improve job coaching, support, training and personal skill development.
- :: Improve transition and education services.
- :: More jobs.
- :: More/low-cost transportation options.
- :: Move day programs away from in-house activities and workshop settings.
- :: Understanding of priority of employment.



focus on employment related activities

What is working well in employment related services?

- :: Employers are becoming more open to employing individuals with developmental disabilities and more jobs are available.

We have helped a lot of people with developmental disabilities find jobs in a variety of settings. Employers see the benefit of hiring individuals with disabilities.

- :: Employment is a priority – there's more awareness of the issue, more activity around it and improved integration and inclusion.

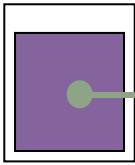
Businesses are finally beginning to get it – people with developmental disabilities can and do make good employees. Most service providers have made employment a primary focus point.

The concept of Supported Employment is beginning to be understood by agencies, employers, staff, consumers and their families as a rewarding and necessary part of true community integration.

- :: Day programs, et al., are offering more work related activities and training.

There are many training opportunities provided by Day Training & Habilitation programs which [help] folks with disabilities succeed in the employment area.

Offering community based and in-center work opportunities, giving people choice.

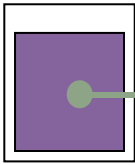


focus on employment related activities

What is working well in employment related services?

:: Other topics mentioned:

- Employees receiving better wages,
- Individualized placement efforts (focusing on individual's interests / better matching),
- Good supports for those with employment,
- Work programs in schools / students with jobs,
- Coordination with rehabilitation counselors / efforts by Workforce Centers and DEED



focus on employment related activities

What needs to be improved in employment related services?

- :: Better awareness and education of employers and community (including more business partnerships and better supports for employers)

More awareness of the importance of employment to persons with disabilities.

Employers need to be educated on ADA and benefits of hiring people with disabilities.

Need to increase business partnerships so there are more direct hires and natural supports.

- :: More / better job coaching, supports, training, personal skills development (including higher salaries for job coaches, more rehabilitation counselors, and more funding)

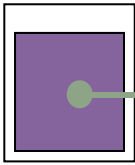
Stronger supports upfront and for the first year, so as to provide the training necessary for the employee, employer and coworkers.

I see a great need for personal skills development; including soft skills and training which will encourage greater self-sufficiency.

Need more rehabilitation counselors so people don't have to wait many months for services.

Support services in which people with experience are assisting in job placement. Most people hired to do this are straight out of college and have no experience.

Pay for staff working in this field is not great – there need to be incentives for people to want to work in this field so that individuals with disabilities have staff to help train them in jobs, take them to jobs, and help them get the jobs they want.



focus on employment related activities

What needs to be improved in employment related services?

:: Improved, more coordinated and earlier transitional education and services

In the past 3 years transitional education has suffered a huge blow and more and more students with disabilities are graduating with little or no job training skills.

There's not enough funding – work programs are being cut – not enough collaboration between schools and vocational rehabilitation / county services.

Earlier experience for people with developmental disabilities would be beneficial. Development of work programs in the schools would allow for individuals to gain experience in the field they choose or desire to be in once they have completed their education.

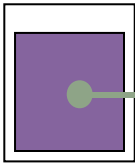
There needs to be a more direct connection between transition programs and employment programs so people get adequate, or at least relevant, training experiences.

:: More community jobs / more jobs (unspecified) and more creativity

More community job opportunities.

There have not been many jobs available or supported employment agencies have not been having luck assisting our clients to find jobs, so they are currently unemployed and on waiting lists.

More programs who think outside the box to provide meaningful and challenging jobs for people, including those with very limited abilities.



focus on employment related activities

What needs to be improved in employment related services?

- :: More transportation options; lower transportation costs

Transportation (and the rising cost of providing it) is of concern.

More transportation options!!

Some individuals can't even apply for jobs if the jobs are too far away or at inconvenient times.

- :: Day programs need to move away from in-house activities / workshop settings

DTHs need to move away from in-house activities and secure employment for the individuals.

Rid the system of typical workshop settings – encouraging individual plans that are for real jobs with real employers.

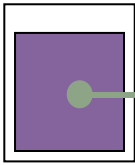
Less 'in-house' type of work and more work in the community.

- :: Understanding of priority of employment – specifically related to flexibility of residence staffing / hours

Residential providers need to be more flexible with home staffing to accommodate hours that an individual is home when they obtain a job.

Residential providers have to place more value on the employment of their clients. They see no problem in removing them from work frequently for appointments, etc.

Individuals need to have the option to stay home until their job starts, rather than being picked up at 7am for a job that doesn't start until 10am. Residences need to move away from the standard 8-2 for day programs.



focus on employment related activities

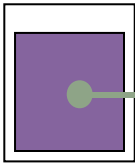
What needs to be improved in employment related services?

:: Other topics mentioned:

- Greater incentives for employers
- More support from Governor / State / County
- Remove sub-minimum wage / better wages
- Employees, schools, and advocacy agencies need better understanding of workplace realities
- More job opportunities in government / non-profits / service providers
- More advocacy
- More funding

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**6::
focus on
health related
activities**



focus on health related activities

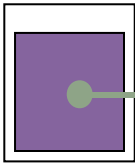
Respondents who reported an emphasis in health related services were also asked to identify what was working well and what could use improvement in this area.

The most commonly identified areas that were working well were:

- :: There are committed healthcare providers.
- :: Minnesota offers quality care, though some work may be required to find it.

The most commonly identified areas for improvement were:

- :: Few doctors accept Medical Assistance.
- :: Healthcare coverage is limited and the payment process is complex.
- :: Transportation is difficult and costly.
- :: Improve physician training in areas specific to developmental disabilities.
- :: More preventative services.
- :: Lack of communication and coordination between providers.
- :: Too many benefits have been cut.



focus on health related activities

What is working well in health related services?

:: There are healthcare providers committed to serving individuals with developmental disabilities.

Doctors are willing to work with providers to meet needs.

There are many skilled and knowledgeable health practitioners in Minnesota.

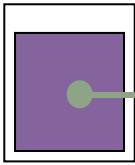
:: Minnesota provides access to quality services and other healthcare options for individuals with developmental disabilities and their families, though sometimes research and work is required to find them.

Minnesota provides some of the best quality services for health, mental health, and human and social services.

More doctors and others are aware of the unique needs of people with developmental disabilities and access to needed services is more available.

Basic health needs are met and providers are available to help individuals and families to jump through the many hoops. Although, sometimes people get good care without having to jump through too many hoops.

Many options are out there if families do lots of research to seek them out.

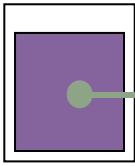


focus on health related activities

What is working well in health related services?

:: Other topics mentioned:

- Low-cost health insurance
- Communication and coordination between providers
- Accompanying clients to appointments and helping with paperwork
- Meeting needs by working with individuals on a one-to-one basis
- Waiver services



focus on health related activities

What needs to be improved in health related services?

:: Few doctors or providers accept Medical Assistance, limiting access to quality healthcare.

There are fewer and fewer dentists available who will accept Medical Assistance payments, and the ones who do, take 6-8 months to get an appointment with.

It is getting harder to find healthcare providers who are willing to work with people with developmental disabilities. The government has such limited reimbursement that many are refusing to serve this population.

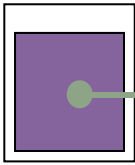
Dental offices that offer Medical Assistance services are few and far between. Often times a person needs to travel 45 to 60 miles to see a dentist.

:: Healthcare coverage is limited, and the payment process is complex.

Costs of programs that aren't billed to Medical Assistance/insurance are often too high for many families to pay.

Funding needs to be available at a higher rate for healthcare services.

Simpler payment system. A one-party payer [system] would cause less restrictions on dental services and mental health services. Coverage for these and other health related services varies widely from insurance to insurance. One-payer insurance would be simpler, easier to determine eligibility and would save administration costs.



focus on health related activities

What needs to be improved in health related services?

- :: Transportation to and from healthcare appointments is difficult and costly.

Transportation difficulties is a big problem for many families and usage of taxis are not effective. This makes families late for appointments or they are unable to make it because their transportation does not show up.

Often times a person needs to travel 45 to 60 miles to see a dentist and public transportation is the only option, it gets costly. These costs for one visit run up to and often over \$100 just for the ride.

- :: Physician training in specific areas such as diagnosing developmental disabilities, communicating with individuals with developmental disabilities, and medical home principles could be improved.

We need to train more pediatricians in the medical home principles. We need to do more training of all physicians on how to communicate information to adults with developmental disabilities.

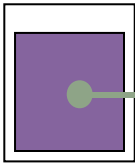
Medical professionals could benefit from having experienced a mandatory internship of some length of time which exclusively serves [individuals with developmental disabilities]. This would allow them opportunity to build relational and investigative skills to assist them in accurately diagnosing maladies.

- :: There is a need for more preventative services.

Money available for more preventative services rather than reactive services.

We need to make sure health care providers actually provide preventative healthcare services (such as pap tests, prostate screening, etc.) to individuals with developmental disabilities.

Proactive [services] rather than crisis interventions.



focus on health related activities

What needs to be improved in health related services?

- :: There is a lack of communication and coordination between various service providers for individuals with developmental disabilities.

Every agency needs to be on the same page in the state of Minnesota, so that when a person moves, he or she will receive the same basic service.

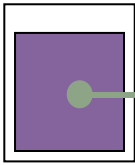
A lot of things are only now getting to be looked at in terms of standardization and consistency... we're not there yet, but we're moving in the right direction.

An acceptance from the health field in allowing input from providers regarding individual needs specific to the person that impacts health care decisions.

- :: Too many benefits have been cut for people with developmental disabilities.

Consumers and their families are being squeezed by cuts in government funding for essential programs. Cuts to Consumer Directed Community Supports have resulted in a deep distrust of government funding.

Cuts in services and the staggering rate of uninsured children is not acceptable and must be changed.



focus on health related activities

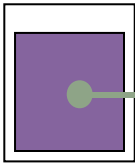
What needs to be improved in health related services?

:: Other topics mentioned:

- Allow more time for the individual with a developmental disability to understand and follow medical procedures
- Educational services for people with developmental disabilities and their families related to healthcare
- More services for Dual Diagnosis
- Eliminate co-pay

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**7::
focus on
self advocacy
activities**



focus on self advocacy activities

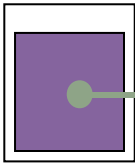
Respondents who reported an emphasis in self advocacy activities were also asked to identify what was working well and what could use improvement in this area.

The most commonly identified areas that were working well were:

- :: There is a variety of self advocacy groups reaching more people in Minnesota.
- :: People with developmental disabilities are becoming increasingly educated and involved.
- :: Conferences promote self advocacy through education and networking.
- :: Individuals are beginning to express themselves and speak out on their own behalf.

The most commonly identified areas for improvement were:

- :: Awareness of existing self advocacy programs.
- :: More public awareness promoting rights of individuals with developmental disabilities.
- :: Others making too many decisions on behalf of individuals with developmental disabilities.
- :: Limited funding restricts self advocacy.



focus on self advocacy activities

What is working well in self advocacy activities?

- :: There are a variety of great self advocacy groups reaching more people in Minnesota.

Many self advocacy groups are active in our area. Our company and others support these groups and provide education on how to be a self advocate.

There is a growing number of People First chapters and active state and metro regional chapters with major activities to provide workshops and conferences.

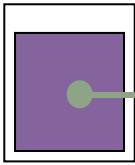
- :: People with developmental disabilities are becoming increasingly educated and involved in their communities and support agencies.

Individuals are getting involved at the grass roots level.

Some agencies – public and private – encourage and provide educational opportunities for client self-advocacy.

Individuals with developmental disabilities witnessing their involvement in the processes that have an impact on their lives; seeing more people with developmental disabilities (actively) involved on local committees, boards, etc.

Consumers are encouraged to participate in advocating for themselves. Our agency has a Consumer Advisory Board that meets every other month with the agency executives to discuss their concerns, likes, dislikes, and plans for the future.



focus on self advocacy activities

What is working well in self advocacy activities?

- :: Conferences, including the annual conference in St. Paul, are helping to promote self advocacy through education, networking, and skill development.

Getting out to a Self Advocacy conference last spring in St. Paul helped; gathering people together and presenting a lot of info about rights and responsibilities helped.

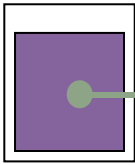
State conferences are helping to build the movement of self advocacy through presentations that build leadership skills. Self advocacy is gaining momentum among consumers and giving them a voice.

- :: As the self advocacy movement increases, individuals with developmental disabilities are beginning to express themselves and speak out on their own behalf.

Clients are speaking up for themselves, sharing their dreams and desires for their future.

Having individuals with developmental disabilities share their own stories.

People have the opportunity to speak on their own behalf.

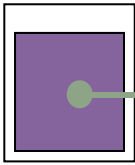


focus on self advocacy activities

What is working well in self advocacy activities?

:: Other topics mentioned:

- Quality and availability of training/workshops provided by self advocacy groups
- Cooperation and coordination between program providers
- Schools establishing self advocacy goals and related activities for students
- Keeping individuals informed of government changes



focus on self advocacy activities

What needs to be improved in self advocacy activities?

- :: Build awareness of existing programs and extend current self advocacy programs to individuals with more challenging physical and mental conditions.

Need to reach out and make people aware of opportunities.

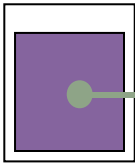
More opportunities need to open up for individuals with developmental disabilities that have challenging behaviors or an additional diagnosis of mental illness.

People with more intense physical and intellectual disabilities may not have the opportunity to participate in self advocacy activities, or may feel excluded from those who [have a less challenging disability].

- :: More public awareness and education promoting rights, self advocacy and inclusion of individuals with developmental disabilities.

Public education is what is needed to include [individuals with developmental disabilities] in their own communities as regular citizens.

More education to the general public about who [these individuals] are and their ability to be a productive part of the community.



focus on self advocacy activities

What needs to be improved in self advocacy activities?

- :: Staff and family members are making too many decisions on behalf of individuals with developmental disabilities.

Reality is that the staff are often determining what is best for the individuals based upon financial limitations of the organization.

I think many times people want to 'take care of' people with disabilities, and therefore the people with disabilities struggle to gain control over what they want, or they stop trying and let others make decisions for them.

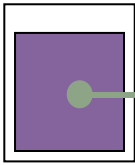
*The biggest issue for me is that families need to step back and reconnect with what the person wants and not what **we** want for them or think is best.*

More individuals need to be making decisions for themselves.

- :: Funding remains a problem and is limited to sources that promote self advocacy.

Self advocacy is under valued, under funded, and under supported. There needs to be funding directly earmarked to self advocacy development, and self advocacy needs to be more of a moral and policy commitment in order that self advocates can share equal power in shaping their own lives with parents, service providers, lawyers and government staff.

There is not enough emphasis on funding to implement self advocacy at the school/parent level. Parents take on too much for their children.



focus on self advocacy activities

What needs to be improved in self advocacy activities?

:: Other topics mentioned:

- Transportation to and from activities
- Individuals should choose their own staff
- More opportunities for minorities
- Schools need to do a better job promoting self-advocacy
- Work on self advocacy after high school