Risk Factors Preventing Persons with Disabilities from Choosing Where to Receive Services and Supports

Minnesota State Quality Council
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For more information contact:

Minnesota Department of Human Services
Disability Services Division
P.O. Box 64967
St. Paul, MN 55164-0967
651-431-2400

Legislative Report

Minnesota Department of **Human Services**

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I. Executive summary

The State Quality Council, led by the Risk Subcommittee, compiled this report to identify major financial and personal risk factors that inhibit individual choice of where to receive DHS funded services and supports. The issues are organized under three main categories: systems issues, provider issues, and individual issues. Each section identifies broad barriers and makes recommendations to DHS about possible ways to address the barriers.

II. Legislation

256B.097 STATE QUALITY ASSURANCE, QUALITY IMPROVEMENT, AND LICENSING SYSTEM, Subd.3(d)(3)(4)

(d) The State Quality Council shall:

(3) identify issues pertaining to financial and personal risk that impede Minnesotans with disabilities from optimizing choice of community-based services; and

(4) recommend to the chairs and ranking minority members of the legislative committees with jurisdiction over human services and civil law by January 15, 2014, statutory and rule changes related to the findings under clause (3) that promote individualized service and housing choices balanced with appropriate individualized protection.

III. Introduction

The State Quality Council (SQC) was created as a result of Mn. Statute 256B.097 Subdiv. 1 and 3. It is assigned the responsibility of assisting the Department of Human Services in meeting the federally mandated requirements for quality assurance of waiver supported programs under section 1915c of the Social Security Act. Specific requirements of the SQC under Subdiv.3 include:

1. Define regional quality councils
2. Carry out quality reviews
3. Create a system for effective incident reporting, investigation, and follow up
4. Assist the Department of Human Services (DHS) in federally mandated Quality Assurance/Quality Improvement (QA/QI) practices
5. Establish QI priorities, recommendations on how to achieve these, and report on these activities annually to the Legislature
6. Identify financial and personal risk issues that impede choice in the selection of HCBS
7. Recommend statutory and rule changes that will mitigate restrictions on choice of service
8. Approve and direct the implementation of a person centered service system
9. Recommend an appropriate mechanism for funding this system
10. Approve measurable outcomes
11. Establish provider licensure periods based on outcomes
12. Transfer Region 10 into an alternative licensing system by July 1, 2013
13. SQC will notify DHS Commissioner when provider assessment has been done and a provider has successfully qualified for licensure
14. SQC will establish an ongoing review process to assess the efficiency and effectiveness of the system
15. SQC may establish a variance from licensing standards process
16. Safety standards, rights, and legal protections of individuals may not be varied. The SQC may make recommendations to the Commissioner or the Legislature regarding changes to these standards, rights, and protections
17. SQC may hire staff to perform these duties

Until funding is available for the core mission of creating an enhanced statewide QA/QI system, the SQC continues working with DHS on other projects related to quality. There are six subcommittees currently working to address some of the responsibilities assigned to the SQC. Although some committee members are paid by their respective agencies to attend these meetings, it should be noted that despite a lack of funding for the State Quality Council some members continue to attend these meetings on a volunteer basis. One committee is reviewing the financial and personal risk factors that inhibit choice in the selection of HCBS services, as required by 256B.097Subd.3(d)(3) and (4) , and one is defining quality indicators to be used in a provider report card that is under development. This report addresses the work of the committee reviewing the financial and personal risk factors.

IV. Systems Issues and Recommendations

A. The reliance on congregate residential settings has stifled the creation and investment in alternative options that support integration in the community for persons eligible for disability waivers.

The system of residential placements for persons with disabilities has been limited. Since Minnesota adopted Home and Community Based Services (HCBS) to move people from institutional placements to community settings, residential options have primarily limited to:

- Staying in the primary caregivers home; or
- Moving to group-based/congregate facilities.[1]

While some other options have been developed, policies and incentives have led to using a few limited models of residential services to the exclusion of other options. While these limitations exist statewide, they are exaggerated in greater Minnesota.

Barriers to Balancing the System of Residential Options

While many stakeholders within the system recognize the need to move away from this historical trend, several barriers exist when trying to balance the system and allow for more self-directed housing options and less reliance on congregate options. These barriers include:

- Financial structure that results in individuals needing to share staff and living space that limits choice.
- Investing in alternative models brings unknown risks. There are a lack of incentives to provide and try other models and there is a lack of trust among many providers that funding will be available into the future for new options.
- The biennium budgeting process limits the ability to spend now to save in the future.
- There are challenges with gathering and analyzing data to see the cost savings of alternative services.
- Workers, teams and families lack information and training on alternatives to traditional services.

Potential Solutions:

Education is needed for people, case managers and providers. The DHS should educate on the CMS Final Rule Compliance and the Olmsted Plan and how it will move people towards more independent living situations. Various providers, lead agencies, and consumers themselves agree

[1] See *Evaluation of Current and Potential Housing Options for Persons with Disabilities*, Disability Services Division Legislative Report, April 2011.

that many persons living in Community Residential Settings[2] are being over-served and could live in more integrated, less structured setting. With proper guidance and services, many individuals with developmental disabilities, brain injuries, physical disabilities, and mental health disabilities could live in a more independent setting and less congregate setting than in licensed foster care settings.

A recent development on the county level is a growth in Independent Housing Options (IHO). This concept refers to a process in which an individual, along with their trusted decision makers, find an apartment, home, or other place to live, and arrange to rent. Then using Medicaid waiver or other services, the individual can find services. The IHO concept is still rudimentary and needs:

- Data that tracks people living in independent living options IHO, shows how they developed the IHO, and reflects and cost savings related to living in the IHO.
- Reform to the current Rate Setting system and the current Consumer Directed Community Supports (CDCS) rate setting methodology for adults, so that individuals living in and IHO do not have to take an overall services budget reduction.
- A study that evaluates total dollars spent on a person over all funding streams as a whole.[3] Pilot studies on moving from less integrated to more integrated settings that emphasize:
    a. Investment in alternatives and incentives for outcomes when people move to more integrated settings.
    b. Training for case managers about and more resources to cover large case loads.
    c. Waiver rates and policies that adequately support IHO.

During the rebalancing effort, it is clear that many individuals will continue to choose group-home models, such as Community Residential Settings, as their preferred setting. As Minnesota implements its transition plan to comply with the HCBS settings rule[4], it will be critical for provider operators, counties, and DHS to share best practices on how to make congregate

[2] Formerly known as Corporate Foster Care settings, Community Residential Settings are defined in MN Stat. 245D.02 as "residential program[s]…where residential supports and services …are provided and the license holder is the owner, lessor, or tenant of the facility licensed according to this chapter, and the license holder does not reside in the facility."

[3] This comprehensive study would look at the cost savings across various state agency budgets – including potential savings in: public safety and police response, Emergency Department visits, medication, provider costs in staff injury and/or property destruction, etc.

[4] For information about the specific CMS regulations visit: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

settings less "institutional" and how to maximize and optimize self-determination and integration for every resident.

B. Case managers have high caseloads and competing duties that often create a disincentive to encourage individuals to consider or create community alternatives.

Case managers are often the driving force on what type of services the individual will receive and where they will receive them. The placement of people with disabilities in Community Residential Settings as opposed to non-congregate alternatives has also largely been driven by case management systems that often emphasize client safety to the detriment of customization and other person-centered approaches that various IHO models require.

Administrative Duties and High Caseloads Dissuade Person-Centered Approaches

There is a lack of intensive training of case managers in person-centered methods, as well as best practices in finding alternative options to congregate living settings. Dual responsibilities for the lead agency in service planning and coordination for the individual, as well as in managing budgets, potentially creates a conflict if a choice requires an increase in funding.

Compounding this problem is that many counties have seen, that when shifting to contracted case management, individuals often receive less individualized attention, because of high staff turnover and the lack of continuity in case management through the contracted provider. While this problem may be more common with contracted case management providers, it is also present in county case management systems.

Potential Solutions:

DHS has compiled nearly seven reports on case management and case management reform over the years.[5] These efforts should be reassessed in light of the significant changes underway in HCBS and other disability services. These efforts should include:

- Pilot alternative models of case management and set specific goals based on increased independence in living situations. Pilot both metro and non-metro models. Use evidence-based practices while developing competency-based training for case managers.
- Separate the administrative functions of case management from the advocacy functions of case management.
- DHS should help ensure there is consistency in the Regional Resource Specialist (RSS) role. This position is a helpful resource for lead agencies and should be expanded to assist in addressing issues across the system.

[5] See, for example, *Minnesota Case Management Reform*, Chemical and Mental Health Services Administration-Adult and Children's Mental Health Divisions and Continuing Care Administration – Disability Services Division, Feb. 2014, revised June 2014.

- Pilot a quality assurance process (like the Region 10 Voice Review process) that evaluates all involved entities that influence the person's quality of service.

C. There is a lack of clarity on what the limits of a guardian are, and how to address it when they are not truly acting in the best interest of the person.

Many people who access disability services are also under guardianship and/or conservatorship. They may have a family member acting in this role, a professional guardian/conservator, or the State may be acting in this role.

While Minnesota Guardianship and Conservatorships statutes do encourage the substitute decision maker to take the protected persons wishes under consideration, in practice, there are few resources to teach people "person-centered guardianship" practices.

Potential Solutions:

Development of evidence-based practices in supported decision making. DHS and counties, in their position as public guardians, are in a unique position to take the lead in creating innovative approaches to person-centered guardianship and alternative decision making, including:

- Pilot a person-centered guardianship project
- Assure that the person-centered plan helps direct the guardianship role
- Share practices with MAGiC[6] and the courts system to promote person-centered approaches throughout the larger guardianship system

D. Traditional approaches to HCBS options have not allowed to effective coordination between all the possible support systems in an individual's life.

By the time many individuals and families access disability services through their local county, they have already experienced a variety of bureaucratic processes. Family members and guardians face complex medical, educational, and human services systems; terminology and processes; and these systems do not work in harmony to help the family. Additional stressors of challenging care, disruption in the caretaker's work life, and additional expenses related to care exasperate the family's capacity to navigate the system. Through navigating the medical and disability systems, and the Individual Education Plan (IEP) through the school system, persons with disabilities are generally overwhelmed and confused with trying to become as independent and self-directed, as possible.

The county system, and a host of state and federal disability benefit programs, provide yet more complex layer for persons to navigate. While all of these systems are designed to help

[6] MAGiC is the Minnesota Association for Guardianship & Conservatorship.

individuals, they rarely work harmoniously. There is little interaction between the medical world, the school-age world, and the post school county-benefits world. Many families and individuals express frustration at the lack of coordinated efforts between these siloed services and the lack of communication between the various professionals providing services to help increase an individual's quality of life and independence.

Potential/Proposed Solutions:

In general, DHS should lead initiatives that:

- Change system philosophy to assume family involvement is ongoing in a person's life and provide training on how to reintegrate people into their natural supports.
- Promote early intervention within families and the entire system (schools, service providers, lead agencies) to include long range planning for services in the future that includes their involvement.
- Provide education for school systems on person-centered thinking.
- Promote better communication between counties on best practices, coordination, and sharing of resources.
- DHS should promote coordinated efforts with the Department of Education to ensure that School districts be involved with person-centered planning.

E. There is a shortage of affordable housing for many people in Minnesota, and a greater challenge for people with disabilities.

The 2011 DHS legislative report evaluating housing options for persons with disabilities found that individuals with disabilities face an immense burden when it comes to finding affordable housing. The study estimated that only 100,000-140,000 units of affordable housing existed for approximate 500,000 Minnesota households meeting the definition of "cost burdened" for housing. Most Minnesotans receiving services through Medical Assistance, unless they receive a housing subsidy, were considered part of this cost-burdened population.[7]

Specific barriers for people with disabilities in entering and staying in traditional real-estate markets

Aside from this very real challenge of having enough money to afford a choice in housing, persons with disabilities may face additional barriers besides being cost burdened, when trying to access housing, including:

- Reluctance by property owners to rent to people with disabilities.
- Lack of credit rental history or poor credit/rental history reduces chances to being accepted as a tenant.
- Matching appropriate units with persons with disabilities has been a challenge.

[7] *Evaluation of Current and Potential Housing Options for Persons with Disabilities*, Disability Services Division Legislative Report, April 2011.

- There is a shortage of real jobs for real pay which significantly decreases options for independent housing.

Potential Solutions:

While solutions to affordable housing shortage are complex and require a variety of stakeholders and solutions, DHS can make immediate changes to help address specific barriers for persons with disabilities, including:

- Increasing access to housing subsidies through reform and balancing of the GRH program and MSA-Housing Assistance program so more people can access more funds to help cover the cost of independent housing.
- Use what was developed and learned by the Arc Housing Access Project to expand those same practices.
- Create a disability housing network to assure that information can be shared and so individuals and families can network and potentially find roommates.
- Public awareness/outreach to show the public that renting to people with disabilities is a positive for landlords and the community.
- Support continued work by the Olmsted Commission on employment issues to help address the issue of affordable housing.
- Provide technical assistance to rural areas that have limited housing alternatives available.

V. Provider Issues and Recommendations

Providers include residential, vocational, day-training, and other providers of services for persons with intellectual and developmental disabilities, brain injury, mental health, or other disabilities. Providers are funded largely, but not exclusively, by Medical Assistance in the form of HCBS waivers, state plan services, or other public insurance programs. Issues identified as system issues include:

A. There is a lack of incentives to assist and encourage people to choose the most independent and integrated options.

Many providers who have invested in foster care homes have not been afforded reasonable incentive to assist individuals in transitioning towards more integrated and independent settings.

Potential/Proposed Solutions:

As quality improvement becomes a greater emphasis and focus, a key measurement of quality is the participant's ability to control their life choices and decisions. Therefore, this should be treated as a quality assurance issue and providers who evoke practices to support and optimize participant self-direction and autonomy should be acknowledged as improving quality in these areas.

Expand the initiatives that DHS already has for moving people into alternatives to adult foster care and Community Residential Settings, because there is a dire need to expand the resources available for this, including:

- Education to providers, lead agencies and families on how to provide alternatives. Perhaps a centralized education resource. Create a Regional Resource Specialist who is available specifically to help the providers and recipients of services.
- Opportunities for families in the school system to connect early and often with the service and support system they will encounter after (or even during) school. This may include inviting the entire support team and team members from the lead agency or future providers into the school to participate in the IEP and other planning meetings. Provide more resources for person-centered planning.
- Provide more resources for everyone – providers, families, individuals, advocates, and professional case mangers on person-centered planning and implementation of person-centered plans.

B. Current polices inhibit residential provider-owners from holding vacancies in foster care placements that might otherwise facilitate greater movement of individuals into more independent settings.

Because Community Residential Setting beds are limited and used mostly for crisis placement, movement within the system is difficult. Individuals are fearful of moving and losing placement,

if the new situation does not work, and counties and providers are under pressure to make sure every vacancy is filled because of the long waiting list for services and residential supports.

Potential Solutions:

As person-centered planning becomes the dominant practice from which to create and execute service plans, and without lifting the moratorium, certain modifications could be made to alleviate the slim percentage of openings and allow for individuals to try and move, with the security of being able to return, if the change does not work. This might require:

- Reimburse providers or beds left open for these purposes and for individual change of status issues.

C. There is a lack of financial support for innovation.

DHS recently awarded HCBS PIPP grants[8] to generate innovative ideas for integrated support for independence. While these types of grants are a step in the right direction, it remains to be seen how effective and efficient these grants can be at generating evidence-supported practices and jettisoning practices that prove ineffective.

Potential Solutions:

For the next round of grants, DHS needs to:

- Provide resources to help providers carefully think through their proposals, and how results will be measured,
- Help providers find assistance for generating new ideas,
- Share some of the upfront costs for innovation,
- Allow longer time periods for projects,
- Require that best practices learned from these are shared and expanded, and
- Create a more comprehensive system that expands on the most successful ideas.

D. There are liability issues related to personal injury or financial loss when individuals exercise choice that may result in a negative outcome.

Providers may view individual choices mainly through the lens of potential liability that they could incur if something negative happens to the individual. Whether potential liability is a reality or just a perceived threat with very low likelihood, it inhibits provider incentive to promote and support individuals striving for more self-determination.

Sometimes fears of liability are not just the provider, but guardian and county as well. Beyond perceive or actual threats of private lawsuits, the requirements of the Vulnerable Adult Act and

[8] DHS has posted information on this program on its website at: http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_180318.

other protection regulations often motivate providers and caregivers to worry about individual safety more than autonomy and self-determination.

Potential Solutions:

Solving these issues will require provider training and communication, as well as robust person-centered planning tools and services. Ideally this barrier could be reduced by:

- Strong person-centered planning to connect the choice/risk to a well-documented and historical set of choices/goals that evolved over time to clearly show how/why the person wants to and may be ready to make a riskier choice.
- Education for providers in identifying exactly what choices and liability concerns are at issue, so the planning team can assess what liability concerns go above and beyond the normal scope of business risk. Providers may also be more comfortable with some liability "shields" in statute for certain kinds of choices that may go above and beyond basic business liability risk.
- Informed consent: This could clear up misunderstanding of regulations that may result in a lack of choice for people. Providers may believe that there are regulations that limit their ability to provide services in a certain manner, when in reality this may not be the case. Inequities in technical support across the state lead to some options being restricted to a few geographic areas. Therefore, the quality of training and access to technical support needs to be increased and consistent.
- Utilization of a quality assurance review process (like the Region 10 model) that empowers teams around the person to determine reasonable risk. This process includes and then emphasizes team control verses standardized and prescriptive licensing criteria that may not represent the person's best interest.

VI. Individual Issues and Recommendations

A. Moving into one's own home or apartment carries certain financial risks, and these may be compounded by other factors related to an individual's disability and need for services.

While congregate settings often limit individual monthly income to approximately ninety-five dollars every month, congregate settings also supply many (but not all) of the basic necessities of daily living. Moving into an independent setting may increase one's monthly spending money, but the burden of paying for unknown expenses and living month-to-month also presents significant risks, including:

- Unpredictable living expenses.
- Lack of roommate network and other informal safety nets to provide natural supports.
- When people do find roommates, any move or change in situation for one will greatly affect the other.

The other burden of relying on government-funded services and income supports is that individuals are forced to remain in poverty because of income and asset limits.[9] It is incredibly challenging to save for future expenses, both because of the amount of money they are allowed to earn, and the limited savings mechanism available if they do have extra money. This makes planning and thinking about a more independent future difficult.

Potential Solutions:

DHS and the state must increase public information about existing programs and expand programs that have proven successful at promoting self-determination, including:

- Robust public resources and one-stop shop for persons with disabilities that has ALL of their options for monetary independence in one place.
- Modify service eligibility rules that prevent individuals from saving sufficient funds to meet large one-time expenses and or prepare for a move to an independent setting.
- Increase eligibility criteria for MA-EPD, while lowering financial burdens on families and individuals, who access MA services.
- Raise the asset limit for persons with disabilities accessing MA services and waivers.
- Create more tools to help people start planning, including the promotion of early education about "navigating" the system by connecting families to resources beyond just school as soon as they access services.

[9] Spell out the income and asset limits for SSI and M.A. Waivers

B. Beyond Financial risks, moving into a more independent setting often requires strong informal supports, finding roommate(s), flexible service providers who can respond to changing needs.

There is not a good network to find a new roommate. People receiving services in general often have more complicating factors that make finding and keeping a roommate more challenging. While roommates should not be a prerequisite to living independently with government-funded services and supports, people who cannot find roommate may need to accept lower quality housing and lower quality of support.

Because of the variability of individual disabilities, any sudden increase in need for services may put the individual at risk of losing housing or a roommate. There is no incentive to try a more independent situation if there is a risk of not having the richer service available again when needed. Case managers often prefer to provide as many services as possible to assure that they will not have many problems.

There are also personal relationships at stake including anxiety, fear, and potential loss of relationships that may not be fully captured in current assessment tools. These feelings are often compounded by a feeling of increased personal responsibility, fear of "failing" in a new environment, and fear of harm and isolation when moving to a less structured setting.

While natural supports (unpaid family and friends) are important, if they are over relied upon to provide essential supports, and then any small disruption occurs, it could put a person's independence at risk.

All of these factors often create a general and overwhelming concern by individuals and their teams, that if a more independent setting is not successful, there will not be a more structured setting available.

Potential Solutions:

The Olmstead Plan has set goals to increase the amount of persons successfully living in more independent settings, and include action steps such as:

- Reforming subsidized housing options in Minnesota (specifically GRH)
- Developing a roommate match network
- Support providers sharing service
- Expanding relocation services and providers, and incorporating best practices learned through pilot projects, such Housing Access Services
- Improving the Housing Link website

In addition, DHS should recognize that, since the residential service and support system has not evolved as fast at the people who need services, more is needed to catch up – including:

- Organizing a network of resources for individuals and families, including harnessing the expertise of people, who have made the transitions to more independence.
- Allow for a more flexible safety net system that may:
    - Allow people to move back, if something doesn't work,
    - Provide a window of time for readjustment
    - Improve the availability and immediate access to crisis resources.
- Plan for this in the initial planning, including, alternative methods for maintaining relationships, and acknowledge that this is part of life.
- Continue to develop alternative forms of supervision such as monitoring technology.
- If team has been attentive in the past they can work to overcome fears before a move. Electronic monitoring can help. Support to overcome fears should be in place. New population coming in to the system may make this less of an issue.

C. Lack of effective and affordable transportation options.

Transportation remains a critical hurdle for persons with disabilities being able to have more self-direction and control over their daily lives. It is also a barrier to moving to more independent settings. Like many other issues in this report, the problems are compounded in greater Minnesota. Transportation issues that are barriers to more self-determinative housing include:

- The limited range of options many people may have, when looking for an affordable place to live on their own because of the need to be close to transit and/or public transportation.
- Rate setting issues cause lack of services to people who live far from provider.
- Insurance coverage often prevents otherwise willing providers or caregivers from providing transportation.
- The limitations of Metro Mobility which includes: limited hours and geographic scope, and eligibility requirements that leave out many individuals with disabilities.

Potential Solutions

These issues however, may be solved by:

- Encouraging transportation from natural supports.
- Simplify the system to allow payment to people who would volunteer to do transportation.
- Incentivize providers who can share/maximize transportation resources.
- Simplify and resolve insurance issues that prevent sharing of vehicles and other insurance concerns.

VII. Conclusion

The State Quality Council urges DHS to consider these and other barriers toward informed choice for individuals with disabilities receiving services and supports through government programs. The Council looks forward to its ongoing work to assist the Department and the Commissioner in creating a person-centered service system that provides the most opportunity and flexibility for persons with disabilities to appropriately balance their health, safety, welfare, and self-determination.