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**MINNESOTA
DEPARTMENT
OF
HUMAN
SERVICES**

**DISABILITY
SERVICES
DIVISION**

Recommendations for Services for Children and Youth with Disabilities

2007 Laws of Minnesota, Chapter 147, Article 6, Section 47

A Report to the Minnesota Legislature

January 2009

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Executive Summary

This report meets the requirements of 2007 Laws of Minnesota, Chapter 147, Article 6, Section 47, to provide recommendations to amend licensure requirements in Minnesota Statutes, chapter 245A, to allow licensure of appropriate services for school-age youth with disabilities under age 21 who need supervision and services to develop skills necessary to maintain personal safety and increase their independence, productivity, and participation in their communities during nonschool hours.

Because of program complexity, the department chose to consider options that went beyond amending license requirements. The department also included recommendations on funding sources for services for this population.

The department reviewed information provided by a county survey, discussed options with a stakeholder group, and conducted research internally to develop the recommendations for services for youth with disabilities during nonschool hours.

The department's recommendations include:

- Support youth with disabilities in participating in activities with other youth, with or without disabilities, whenever possible
- Add Youth Therapeutic Support Service to the disability waivers (CAC, CADI, DD and TBI) to allow for a service with three components:
 1. Integration and inclusion in the individual's community, as defined in the youth's Community Support Plan
 2. Training and supports to the family to allow them to continue teaching skills to the child or youth in the family home
 3. Support in a non-integrated, congregate setting to allow for an environment where youth can focus on learning specific skills. This portion of the service cannot comprise the majority of the service.
- Require parents of youth 12 years old or younger to pay typical costs for child care.

Legislation

This report is submitted to the Minnesota Legislature pursuant to 2007 Laws of Minnesota, Chapter 147, Article 6, Section 47.

*Sec. 47. **LICENSURE; SERVICES FOR YOUTH WITH DISABILITIES.***

(a) Notwithstanding the requirements of Minnesota Statutes, chapter 245A, upon the recommendation of a county agency, the commissioner of human services shall grant a license with any necessary variances to a nonresidential program for youth that provides services to youth with disabilities under age 21 during nonschool hours established to ensure health and safety, prevent out-of-home placement, and increase community inclusion of youth with disabilities. The nonresidential youth program is subject to the conditions of any variances granted and to consumer rights standards under Minnesota Statutes, section 245B.04; consumer protection standards under Minnesota Statutes, section 245B.05; service standards under Minnesota Statutes, section 245B.06; management standards under Minnesota Statutes, section 245B.07; and fire marshal inspections under Minnesota Statutes, section 245A.151, until the commissioner develops other licensure requirements for this type of program.

(b) By February 1, 2008, the commissioner shall recommend amendments to licensure requirements in Minnesota Statutes, chapter 245A, to allow licensure of appropriate services for school-age youth with disabilities under age 21 who need supervision and services to develop skills necessary to maintain personal safety and increase their independence, productivity, and participation in their communities during nonschool hours. As part of developing the recommendations, the commissioner shall survey county agencies to determine how the needs of youth with disabilities under age 21 who require supervision and support services are being met and the funding sources used. The recommendations must be provided to the house and senate chairs of the committees with jurisdiction over licensing of programs for youth with disabilities.

Background

Defining the Scope of the Question

The legislature required the department to make recommendations to allow licensure of services for school-age youth with disabilities under age 21 and to survey counties to determine how the needs of youth with disabilities under age 21 are being met and the funding sources used.

Because of program complexity, the department chose to consider options that went beyond amending license requirements. The department also included recommendations on funding sources for services for this population.

The department chose to define the scope of the recommendations to include children and youth with disabilities from birth to age 21, who need supervision and support services during nonschool hours. Nonschool hours was defined as the time the school is not responsible for the youth (that is, after school, holidays, summer vacations, etc.).

Stakeholder Group

In order to have comprehensive recommendations to fit the scope of the report, the department decided to convene a stakeholder group to assist with development of the county survey, discussion of policy issues, and development of recommendations. The group consisted of advocates, providers, counties and DHS staff. A list of the individuals who participated in the stakeholder group is included in Appendix A. The stakeholder group met three times throughout the summer and fall of 2008. DHS staff informed the stakeholders that the department is responsible for making the recommendations and sought input from them in drafting the recommendations. DHS staff made a commitment to the stakeholder group to include their recommendations in the report if there was a difference between the recommendations of the stakeholders and the final department recommendations. Appendix B includes the complete list of stakeholder recommendations, although many of the recommendations of the stakeholder group are incorporated into the department recommendations beginning on page 10 of this report.

County Survey

The legislature required the department to survey county agencies to determine how the needs of youth with disabilities under age 21 who require supervision and support services are being met and the funding sources used. The stakeholder group assisted the department with defining youth with disabilities and with development of the survey. It was decided that the survey would ask about youth with the following disabilities:

- Brain injuries
- Chemical health conditions
- Chronic health conditions
- Developmental disabilities
- Mental health conditions
- Physical disabilities

The survey asked about children in the following age categories:

- Ages 0-5 (early intervention)

- Ages 6-11 (school age)
- Ages 12-21 (school age with transition planning)

The online survey was distributed to county agencies through the department's Regional Resource Specialists (RRSs), who provide ongoing training and technical assistance to each county. There was no limit on the number of responses that each county could submit, and county staff were encouraged to forward the survey to the most appropriate people to answer for each population. Because the initial survey response was limited, the survey link was reopened and a request for information was sent to specific county staff in areas of the state where there was a low response rate.

There were 103 responses to the survey, representing 43 counties, in all parts of the state. Responses addressed all identified disability types and age groups. 28 of the responses were from Hennepin County. Table 1 provides a summary of the survey responses by disability type and age group.

Table 1- Number of Survey Responses by Disability Type and Age Group

	Ages 0-5	Ages 6-11	Ages 12-21	Total
Brain injuries	24	32	35	91
Chemical health conditions	9	11	24	44
Chronic health conditions	29	34	40	103
Developmental disabilities	53	66	76	195
Mental health conditions	37	47	54	138
Physical disabilities	39	53	58	150
Total	191	243	287	721

Appendix C provides a map showing the locations of the responses. Appendix D provides the complete statewide survey results.

Current Services

Individuals with disabilities in Minnesota may be eligible to receive services through Medical Assistance (MA or Medicaid) state plan or through the four home and community-based waivers for individuals with disabilities. The four disability waivers are:

- Community Alternative Care (CAC)
- Community Alternatives for Disabled Individuals (CADI)
- Developmental Disabilities (DD)
- Traumatic Brain Injury (TBI)

The services available through MA state plan and the four disability waivers are intended to provide an individual with supports to allow them to remain in the community.

Data is available on the number of youth from birth through age 21 currently receiving services through Medical Assistance (MA or Medicaid) state plan services and through the four home and community-based waivers for individuals with disabilities. Table 2 provides a statewide summary of these numbers. Table 2 does not provide an unduplicated count, but total numbers of recipients, by age, for each funding source.

Table 2- Total Youth Currently Receiving Waiver and State Plan Home Care

	Age 0-5	Age 6-11	Age 12-14	Age 15-18	Age 19-21	Total
State Plan PCA	1170	2827	1267	1306	692	7262
State Plan PDN	203	97	40	44	37	421
CAC	97	68	32	30	30	257
CADI	224	599	363	538	542	2266
DD	43	729	684	1072	878	3406
TBI	8	11	19	33	52	123
*Family Support Grant (FSG)						1627

Data as of 01/14/2009

*Data as of 02/01/2007; data does not provide a break out by age category

County survey results, discussion with stakeholders, and research within the department were used to determine what services are currently available to youth with disabilities during nonschool hours.

Waiver and state plan home care rules permit youth with disabilities to access supports to attend traditional youth programs, such as Personal Care Assistant (PCA), In-home Family Support, Independent Living Skills (ILS), and Personal Support. Examples of these programs include traditional child care programs, after school programs, and after school activities with peers. These services can also be used to provide one-on-one support to youth with disabilities in their home or in the community.

Discussions with stakeholders and review of county surveys, however, showed that it is often difficult to find traditional programs that will accept children and youth with disabilities, even with additional supports. Many child care and other programs for children and youth can justify an exemption to the requirements of the Americans with Disabilities Act (ADA) under the undue burden provision of the law because they are very small businesses with little revenue to cover extra staff, insurance, or physical plant changes.

According to the county survey results, many youth with disabilities who are receiving support during nonschool hours are receiving one-on-one support in the family home or in the community, but they are often not participating in activities with other children. Services that are currently being used to support youth in this manner include:

- Medical Assistance (MA or Medicaid) state plan home care services, including Personal Care Assistance (PCA) and children's mental health services
- Consumer-directed community supports (CDCS) through the disability waivers
- Extended home care services through the disability waivers
- Respite through the disability waivers
- Independent Living Skills (ILS) through the Community Alternatives for Disabled Individuals (CADI) and Traumatic Brain Injury (TBI) waivers
- Consumer training and education through the Developmental Disabilities (DD) waiver
- In-home family support through the DD waiver
- Personal support through the DD waiver

Some counties indicated that they do not currently provide disability waiver services to many children or youth because waiver allocations are limited. Counties are required to use waiver allocations for persons with the highest need level or have met other identified priorities. The individuals who meet the priorities are often adults that cannot live, or do not have an option to live, in their family home. However, as identified in Table 2, there are over 6,000 youth currently receiving services from the disability waivers (CAC, CADI, DD and TBI).

Service Gaps

The department used county survey results and discussions with stakeholders to identify gaps in the services available to youth with disabilities. One service gap is the ability for youth with disabilities to participate in group activities with peers with or without disabilities. Often youth with disabilities are not able to attend traditional programs for children due to a high need level, such as complex medical conditions or behavioral needs. Some counties and stakeholders noted that it is somewhat easier for younger children with disabilities to find group or community activities than for older children and youths with disabilities. Older children and youths with disabilities find it more difficult to participate in nonschool activities and programs if their physical, mental, or social development lags behind their age peers, because these activities and programs often assume or require a higher level of competence, such as athletic skill, in order to participate.

In many counties, youth with disabilities often receive services in their home with a staff person, rather than in an existing group activity with children without disabilities. Being in their home with a staff person does meet the needs for some youth who are integrated with their peers through other activities and have needs in areas that may be met in their home; however, other youth may need support to be integrated with their peers and within their communities.

Parental Responsibility

The stakeholder group and DHS staff discussed the responsibility of parents to pay costs for their children to have supervision. The department's position is that parents of all children 12 years old or younger are required to provide supervision or arrange for supervision when they are not available. This includes paying for child care costs when the parent is working or otherwise unavailable. The department recognizes that parents of children with disabilities often have additional costs that parents of children without disabilities do not have, including health care costs and parental fees for their children to have access to Medical Assistance; however, these additional costs do not change the requirement of parents to pay for child care costs. There are

parents of children with disabilities who also have these additional costs, and are still responsible to pay child care costs when their child is able to attend a typical child care or other child care setting. The department reviewed funding options available to parents with the stakeholder group, including the Child Care Assistance Program administered by the department, which is available to parents of children with disabilities if they meet the income requirements of the program.

Recommendations

Department Recommendations

The goal of the department is to provide supports to children and youth with disabilities to assist them with remaining in or returning to their family home, whenever possible. The department recognizes that it is important to provide support to the family as well as the child or youth to allow that to occur. This meets the policy direction of the department and also fiscal priorities of the department. By providing supports to youth and their families in the family home, the state is able to help maintain natural supports, while avoiding costly out-of-home placement for the youth.

The first priority is to provide supports to youth with disabilities to allow them to participate in activities that are typical of youth of a similar age. During nonschool hours, this may involve providing additional support staff to accompany the child or youth to typical child care, after school programs, or other integrated activities.

Home and Community-Based Service Waivers

For children and youth who are receiving services through the disability waivers (CAC, CADI, DD and TBI), or services through the Medical Assistance state plan, supports to attend typical settings and activities for youth are currently available through the use of various services, including PCA, Independent Living Skills (ILS), In-Home Family Support, and Personal Support.

However, there are instances when a child or youth with disabilities cannot be served in a typical, integrated environment, even with staff support, due to the individual's high level of need. In these instances there is a gap in the current services that are available. The primary service model available for children and youth with disabilities who are not able to participate in activities with their peers without disabilities is to have one-on-one staff support at home or in the community, where the youth interacts only with a staff person and not with other youth with or without disabilities. This can lead to social isolation at an age when interacting with peers is very important for an individual's social development. The stakeholders and the department agree that it may be important for a child or youth to have the ability to learn skills outside of the typical environment in order to prepare them for integration in their community.

In these instances, when the child or youth cannot participate in activities with their peers without disabilities due to a need to develop skills, the department's recommendation is to provide services to support youth through three components. The three components include:

1. The primary goal of the service is integration and inclusion in the individual's community, as identified in the individual's Community Support Plan. This would involve providing support, as needed, to the youth while they are participating in group activities with peers with or without disabilities, or in other community activities.

2. The service will require the provision of training and supports to the family, so they are able to continue teaching skills to the child or youth in the family home when staff is not present.
3. The service will allow for supports to be provided in a non-integrated, congregate setting to allow for an environment where the youth can focus on learning specific skills.

The first two components of the support must comprise the majority of the support to the individual. How the first two components are managed for the individual will depend on the youth and their family's needs, as identified in the individual's support plan. The third portion of the support cannot comprise the majority of the service, as the focus must be on integration in the community, as identified in the individual's support plan.

For youth receiving services through the CAC, CADI, DD and TBI waivers, the first two components will be covered through existing waiver services, such as Independent Living Skills (ILS), In-Home Family Support, or Family Training, Education and Counseling.

The third component shall be provided through a new service, potentially called Youth Therapeutic Support Services, which could be added to each of the disability waivers. This service shall only be accessible when the first and second components are provided through the appropriate services, as identified above.

The department recommends that the provider standards for the new service be twofold to include licensure or certification of the service and licensure of the site. For the DD waiver, the service will have a 245B license. It will be a new service class under the standards in Minn. Statute 245B. There may need to be modifications to the existing 245B language to account for this type of service. For the CAC, CADI and TBI waivers, the service must have a certification, as identified in Minn. Statute 256B.49, subd. 16a.

There is an alternative to 245B licensure in a portion of the state. The Region 10 Quality Assurance Commission (QAC) currently conducts a review similar to what is completed by the state to assure compliance with 245B standards. The recommendation is for the department and the Region 10 QAC to develop alternative licensing standards for the Youth Therapeutic Support Service and require compliance monitoring to be completed by the Region 10 QAC. This is a similar process to what currently occurs for other services that would traditionally be licensed under 245B licensing standards.

The site for the non-integrated, congregate setting must have a child care license. The current Group Family Day Care license applies to children ten years of age or younger. The current Child Care Center license applies to children twelve years old or younger. The department currently does not have the authority to permit a variance to the maximum age allowed by the license. The department's recommendation is to allow the commissioner of Human Services to vary the maximum age requirement when the site will be used for the Youth Therapeutic Support Services, up to age 22, to coincide with school attendance. The recommendation is to use the variance process, instead of increasing the maximum age in statute, because the department

wants to ensure that the providers who are allowed to provide waiver services to children over age 12 meet the qualifications to provide this service.

The site will have either a Group Family Day Care license, meeting the requirements in Minn. Rule 9502.0300 to 9502.0445, which is administered at the county level, or a Child Care Center license, meeting the requirements in Minn. Rule 9503.0005 to 9503.0170, which is administered at the department level, depending on the type of site that will house the service. The recommendation is to keep the current child care capacity allowed under the child care license of up to fourteen youth, depending on the size of the setting, for the Group Family Day Care license, or as defined by the Child Care Center license. The capacity limitation relates to the number of children or youth present at any one time and is not a limit on the number of children or youth enrolled with the provider. If the provider chooses to provide other waiver services in the setting, such as respite, the capacity limit for that service will continue to be four. To meet the requirements for each service, the provider will be required to identify specific hours of operation for the Youth Therapeutic Support Service.

The department recommends that providers of the Youth Therapeutic Support Service be allowed to use one set of staff to meet the staffing requirements, including ratios and training standards, for both types of licenses. This would prevent unnecessary duplication in staffing numbers for the providers.

Adding Youth Therapeutic Support Service to the disability waivers (CAC, CADI, DD, and TBI) would require waiver amendments to each of the waiver plans, as well as an increase in appropriations to the disability waivers for the cost of adding this service. Prior to submitting a waiver amendment to the Centers for Medicare and Medicaid Services (CMS), the amendment will need to go through an internal review process at the department, and be released for a 30-day public comment period. Depending on timing, the addition of the service may occur during a waiver renewal instead of submitting a separate waiver amendment. Waiver renewals occur every five years for each waiver and go through the same internal review process and 30-day public comment period.

Implementing the recommendations to the licensing standards will require changes to 245B and child care licensing statutes.

Medical Assistance State Plan Services

For children and youth who are not receiving services through the disability waivers, but who are receiving services through the MA state plan Personal Care Assistance (PCA) Program, the intent of the service is to assist eligible recipients to remain independent in the community. Time is assessed based on the individualized need for assistance in accomplishing activities of daily living (ADLS), instrumental activities of daily living (IADLS), health related functions, and observation and redirection for identified severe behaviors.

A PCA may accompany a child to a child care setting when there is an individualized need for assistance that is unable to be met by the child care staff. The goal of the PCA service is to provide assistance; not to provide skill building or teaching. A PCA cannot be considered the

staff of a child care setting; they are there with a particular child to provide assistance to that child. A PCA may accompany a child to the type of setting described in this report, as they would accompany a child to a typical child care setting. However, additional time won't be prior authorized specifically to attend the child care setting, so the child's parents will need to choose whether the assessed PCA services will be provided in the child care setting or in the child's home.

For children and youth who qualify for Children's Mental Health services through the Medical Assistance (MA) state plan, Children's Therapeutic Services and Supports (CTSS) may be used to provide training and support to the individual and their family in the family home and/or group setting. Each provider who has an interest in providing this service will be required to receive a CTSS certification from the Department of Human Services. CTSS covers rehabilitative services for children who have a mental health diagnosis that meets the criteria of emotional disturbance based on a comprehensive diagnostic assessment that recommends specific skills training to return the child to a normally expected developmental trajectory. CTSS does not cover services that are primarily recreation oriented or provided in a setting that is not professionally supervised (such as sports activities, exercise groups, craft hours, leisure time, social hours, meal or snack time, trips to community activities, and tours). CTSS also does not cover social or educational services that do not have or cannot reasonably be expected to have a rehabilitative outcome related to the child's emotional disturbance.

Parental Responsibility

For children 12 years old or younger, parents will be required to pay child care costs for the service. The department considers it to be normal parental responsibility to pay for child care costs for youth 12 years old or younger.

Stakeholder Recommendations

The department chose to adopt and forward to the legislature a majority of the recommendations that were developed by the stakeholder group; however, there were stakeholder recommendations that the department did not choose to include that are described below.

The first recommendation from the stakeholder group that the department chose not to adopt is related to the licensure of the congregate setting in the Youth Therapeutic Support Services. The stakeholder group recommended that the site receive a Group Family Day Care license, which is administered by the counties. The stakeholder group was cognizant of the state budget situation and was clear in their discussion that they would like to avoid a cost to the state. The department felt it was better policy to license the site following current standards, as a Group Family Day Care or a Child Care Center. The Child Care Center license is administered by the state rather than the county, so there would be a cost to the state to expand the license to this service.

The second stakeholder recommendation that the department chose not to adopt was to change the maximum age for the child care license from age 12 to age 21 for the new service. Instead, the department recommends keeping the existing language, but permitting the department to vary the maximum age for specific providers. This would allow the department to ensure that

providers who are providing services to youth over age 11 meet the waiver qualifications to provide the Youth Therapeutic Support Service.

The complete list of the stakeholder group's recommendations is included in Appendix B of this report.

Conclusion

This report meets the requirements of 2007 Laws of Minnesota, Chapter 147, Article 6, Section 47. The department reviewed information provided by a county survey, stakeholder discussions and internal research to develop recommendations for services for youth with disabilities during nonschool hours. The department's recommendations include:

- Support youth with disabilities in participating in activities with youth with or without disabilities whenever possible
- Add Youth Therapeutic Support Service to the disability waivers (CAC, CADI, DD and TBI) to allow for a service with three components:
 4. Integration and inclusion in the individual's community, as defined in the youth's Community Support Plan
 5. Training and supports to the family to allow them to continue teaching skills to the child or youth in the family home
 6. Support in a non-integrated, congregate setting to allow for an environment where youth can focus on learning specific skills. This portion of the service cannot comprise the majority of the service.
- Require parents of youth 12 years old or younger to pay typical costs for child care.

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Appendix A: Stakeholder Group Members

Sue Benolken	DHS, Children's Research, Planning & Evaluation Division
Karen Erickson	DHS, Licensing Division
Connie Erlandson	DHS, Disability Services Division
Katherine Finlayson	DHS, Licensing Division
Anne Henry	Disability Law Center
Pete Klinkhammer	Brain Injury Association
Steve Larson	ARC of Minnesota
Jeff Lewis	Ramsey County
Kerry Ruesgen	Winona County
Denny Theede	Home Care Options, a provider in Winona County

Heidi Hamilton (Project Coordinator)

Gail Dekker (Facilitator)

Others Who Have Attended One or More Meetings

Karen Bunkowski	Winona County
Jason Franklin	ARSYS, a provider in Anoka County
Mary Jansen	Home and Community Options
Jerry Kerber	DHS, Licensing Division
Tina Richter	Home and Community Options
Cindi Wiczek	Home and Community Options
Peter Walsh	Home and Community Options (for TA)
Leah Zoladkiewicz	DHS, Disability Services Division

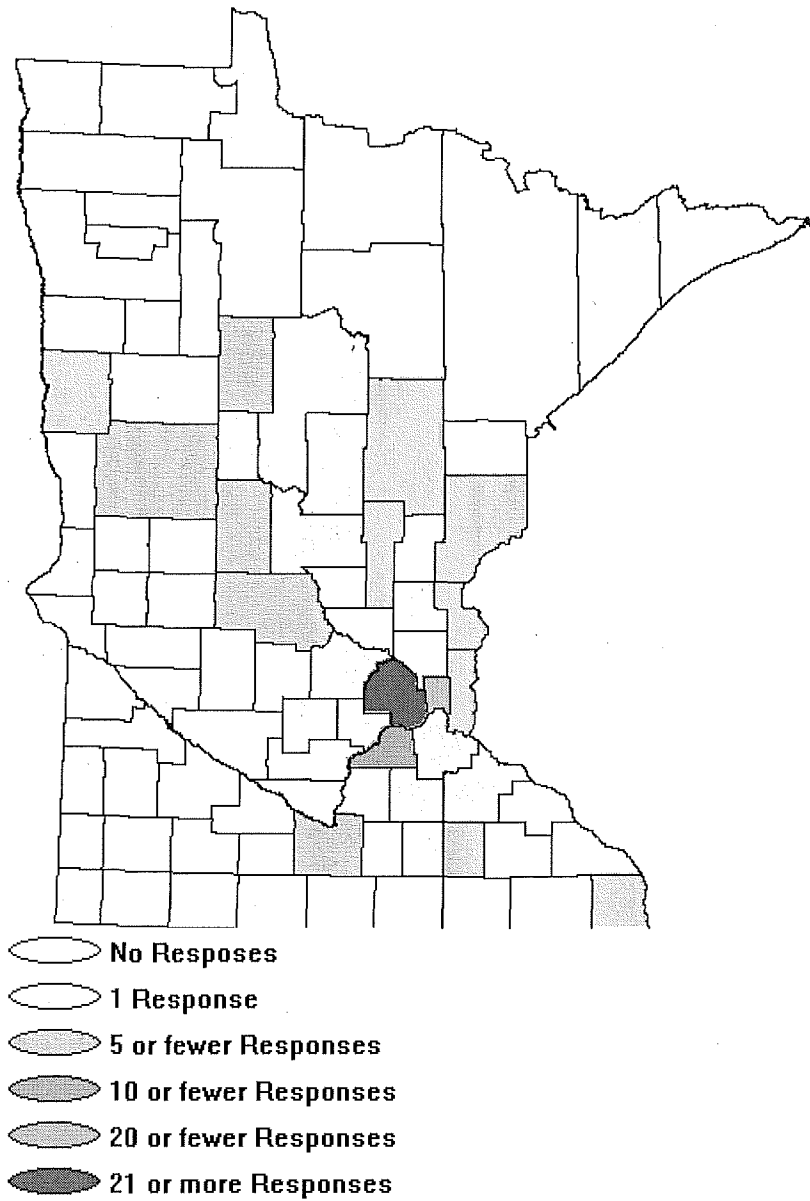
Appendix B: Complete List of Stakeholder Recommendations

1. Establish a new category within the existing license for group family day care (group family day care for youth with disabilities aged 11-21) which is licensed through county agencies to meet these needs:
 - A. Provide supervision and support to youth with disabilities
 - B. Require an individual plan for community integration
 - C. Permit parents to work
 - D. Meet youths socialization needs and preferences
 - E. Offer training/habilitation to foster greater community integration
 - F. Support the family to maintain their child at home and avoid out-of-home placements
 - G. Involve family in learning skills to reinforce habilitation
 - H. To the extent feasible, promotes coordination with all service providers, whether family, school, or human services. At minimum, make school aware of outside services.
2. Add a new service under the waiver with a 245B certification that offers habilitation training and meets basic health and safety needs and includes family support. No new license will be needed. Providers that have a 245B license will be allowed to certify that they will apply the relevant portions of 245B to the new service. Providers of CAC, CADI and TBI waiver recipients, that do not have a 245B license, will be certified, as defined in Minnesota Statute 256B.49, subd. 16a.
3. License service capacity—and not enrollment capacity—for youth aged 11-21 should mirror the up to 14 allowed for children less than 11 year of age.
4. Continue to use child foster care license for overnight respite that is limited to four youth in one residence.
5. Enable youth aged 11-21 who are assessed to be eligible for PCA services to access this new service and be accompanied by their PCA.
6. Revisit the 245B.07 Subd 4 requirements related to supervision/oversight, staff qualifications and designated coordinator duties to design the right qualitative work experience to mentor other staff.
7. Check 245B.06 Subd 2 (risk management plan) to ensure there are adequate staff to meet the needs of youth age 11-21 based on the person's assessed need. We may want to add a paragraph related to this proposed new service.
8. Check 245B.06 Subd 1 related to outcome-based services to clarify intent and practical impact to encourage peer socialization and community integration. Possibly add new item or language?
9. If parents are responsible for payment of child care costs for their children aged 11 and younger, then don't require a duplicate or overlay with additional cost for the habilitation standard or licensing standard. This is not financially feasible for providers. Meet staffing ratios and raise staff qualifications of child care staff to meet the needs of these children. Licensing Division would look at child care ratios, children's habilitation plans, and staff competency to meet child's individual habilitation plan as measures of compliance.
10. Require group family child care license with appropriate exemptions from duplicative child foster care license requirements (as described in Item 9)

11. Amend waiver plans.
12. Need a name for service. Perhaps: "therapeutic support services for youth with disabilities"?
13. Amend PCA statute, if necessary. Not all group members agreed that the statute would need to be amended, if the setting is not defined as an institution.
14. Apply 245B standard for all Disability waivers for this service and allow providers to certify that they will apply 245B program standards to the new service.
15. Determine if a fiscal note is needed for this service. Goal of group was to avoid this.

Appendix C: Map of Responses

Youth Assessment Survey Responses – November 2008



Appendix D: Statewide Survey Results

Disability Services Division Youth Needs Assessment Survey October 2008

1. Please check one or more to indicate your role or responsibilities around services to youth. Within your agency, which age groups would you say you are responsible for...

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 18
Setting policy for youth services	20	23	29
Applying for state and/or federal funds for youth services	31	36	42
Working directly with youth	31	41	54
Other	25	30	38

Please indicate your role or responsibility around services to youth and what age group you work serve.

- Assessing/Coordinating for Rule 185 Case Management and MR/RC Waiver Services.
- Assessments for MA Home Care and waiver programs. Case management for waiver. All ages.
- case management
- Case management
- case management with 18-21 transition unit
- Case management, service coordination, crisis services, management
- DD Access (Intake) - Eligibility determination, screening and service setup for children 3-18.
- DD case management birth and on up
- DD Case Manager birth thru 21 (and beyond) and coordinator for the Family Support Grant
- I work with children and adults on waivers: DD,CADI,CAC
- LTC waiver case management for disabled youth of all ages.
- Parent support program, work with youth around attaining appropriate services if possible
- Social Services Supervisor Children and Family Services including children's mental health and child protective services.... birth to 21.
- Social Worker
- Social Worker / Case Manager DD
- Social worker/ rule 185 case manager/ work with all waiver programs--CAC/CADI/DD/TBI/ birth to age 18 years

2. For what county/counties are you completing this survey?

2 Aitkin	0 Marshall
0 Anoka	1 Martin
0 Becker	0 Meeker
0 Beltrami	2 Mille Lacs
0 Benton	1 Morrison
0 Big Stone	0 Mower
2 Blue Earth	1 Murray
0 Brown	1 Nicollet
0 Carlton	0 Nobles
1 Carver	0 Norman
1 Cass	1 Olmsted
1 Chippewa	5 Otter Tail
2 Chisago	0 Pennington
3 Clay	2 Pine

0 Clearwater
 0 Cook
 0 Cottonwood
 1 Crow Wing
 1 Dakota
 2 Dodge
 0 Douglas
 1 Faribault
 0 Fillmore
 1 Freeborn
 1 Goodhue
 0 Grant
 28 Hennepin
 2 Houston
 3 Hubbard
 1 Isanti
 0 Itasca
 0 Jackson
 0 Kanabec
 0 Kandiyohi
 1 Kittson
 0 Koochiching
 0 Lac Qui Parle
 1 Lake
 1 Lake of the Woods
 1 LeSueur
 1 Lincoln
 1 Lyon
 1 McLeod
 0 Mahnomen

0 Pipestone
 0 Polk
 0 Pope
 11 Ramsey
 0 Red Lake
 0 Redwood
 0 Renville
 1 Rice
 1 Rock
 0 Roseau
 0 St Louis
 7 Scott
 0 Sherburne
 0 Sibley
 2 Stearns
 1 Steele
 0 Stevens
 0 Swift
 2 Todd
 0 Traverse
 0 Wabasha
 1 Wadena
 0 Waseca
 4 Washington
 0 Watonwan
 1 Wilkin
 0 Winona
 1 Wright
 0 Yellow Medicine

3. For which of the following populations are you completing this survey? Check all that apply.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 17
Brain injuries	24	32	35
Chemical health conditions	9	11	24
Chronic health conditions	29	34	40
Developmental disabilities	53	66	76
Mental health conditions	37	47	54
Physical disabilities	39	53	58

4. Non-school hours are defined as the time the school is not responsible for the youth (e.g., after school, holidays, summer vacations, etc.). During non-school hours, to the best of your knowledge based on what you know or have heard:

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 17
For which age groups who have brain injuries, if any, does your county currently fund services during non-school hours	16	16	15

For which age groups who have brain injuries, if any, does your county have a way to identify a need for services during non-school hours?	19	20	22
For which age groups who have brain injuries, if any, has your county identified unmet needs for services during non-school hours?	12	18	19

5. **What barriers exist to developing services during non-school hours for youth with brain injuries, if any?**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Lack of funding for the services	19	25	29
Lack of providers for the services	19	24	25
Lack of resources to develop the services	17	22	22
Other	2	3	4
None	2	2	2

Please describe the other barriers to developing services during non-school hours for youth with brain injuries.

- No money. No providers (because of no money)
- Transportation to activities

6. **Please indicate how these services are usually funded. Check all that apply.**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CAC Waiver	9	9	9
CADI Waiver	11	14	16
County funds	9	11	10
DD Waiver	13	15	14
MA state plan home care services (SNV, PDN, HHA, Therapies, PCA, Mental Health)	14	16	16
Parents or family members	15	16	15
School systems	8	8	8
TBI Waiver	11	12	13
Other	1	1	1

Please specify in what other ways these services are funded.

0

7. **Please check the CAC Waiver services used to provide the services during non-school hours to youth with brain injuries.**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	6	6	6
Extended Home Care Services	5	5	5
Respite	6	6	6
Other	0	0	0

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county..

0

8. **Please check the CADI Waiver services that are used to provide the services during non-school hours to youth with brain injuries**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	9	13	12
Extended Home Care Services	8	11	12
Independent Living Skills (ILS)	5	7	10
Respite	8	11	10
Other	2	2	2

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county.

- Currently, I do not have any TBI Waivers on my caseload. Although, we are available to have them, if there are any that are eligible.

9. Please check the DD Waiver services that are used to provide the services during non-school hours to youth with brain injuries.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	8	12	12
Consumer Training and Education	6	8	9
Extended PCA	9	11	12
In-Home Family Support	10	12	13
Personal Support	5	8	9
Respite	8	11	12
Other	1	2	2

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county.

0

10. Please check the TBI Waiver services that are used to provide the services during non-school hours to youth with brain injuries.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	8	10	11
Extended Home Care Services	8	8	9
Independent Living Skills (ILS)	6	6	9
Respite	9	10	11
Other	3	3	3

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county.

- Assistive technology
- Behavioral support and training.
- Since I don't have any kids on the TBI waiver yet, I can't answer this question.

11. Briefly describe the services for youth with brain injuries during non-school hours. Please include information on the setting, ratio, supervision level, availability (hours and days) of the program and involvement with non-disabled peers.

- I don't believe our county has a formal program; in general, if working with a family with a child having these needs we look to be creative with obtaining an individual service provider to assist in accommodating the need.
- IIs at a supervision level appropriate to meet their needs, may be shared or 1:1
- Individualized service with 1:1 staff with ma home care or waiver CDCS staff. I don't know of any non-school provider specific to brain injury for youth. Brain injury association support programs for youth and families. There is a lack of supports and trained providers with knowledge and expertise to work effectively with brain injury population.
- It depends, it varies on the client
- No information available
- Services are organized by providers. A community setting with 1:1 supervision. Youth services are scheduled by parent. School services do not offer support for youth along side their peers.
- Since I don't have any kids on the TBI waiver yet, I can't answer this question.
- Some social/rec programming-but depends on availability of parent or support person to also attend, if needed. Rehab services for older youth to evaluate employment needs.
- Summer camps, community education, specialized day care, nanny services, tutoring

12. **Non-school hours are defined as the time the school is not responsible for the youth (e.g., after school, holidays, summer vacations, etc.). During non-school hours, to the best of your knowledge based on what you know or have heard:**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Does your county currently fund services during non-school hours for youth age 0 -21 years who have chemical health conditions?	0	1	8
Does your county have a way to identify youth age 0 - 21 years who have a need during non-school hours for services due to chemical health conditions?	2	4	12
Has your county identified youth age 0 - 21 years who have chemical health conditions and unmet needs for services during non-school hours?	0	2	12

13. **What barriers exist to developing services during non-school hours for youth with chemical health conditions, if any?**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Lack of funding for the services	3	10	21
Lack of providers for the services	2	6	15
Lack of resources to develop the services	4	9	20
Other	1	3	4
None	0	0	0

Please describe the other barriers to developing services during non-school hours for youth with chemical health conditions.

- I am not sure who all would need it, transportation to get the kids to the service, and the teens willingness to go and stay at the service.
- Transportation, creating and keeping interest in the youth to participate
- Transportation, lack of participation, parent involvement, community outreach to at risk youth and families

14. **Please indicate how these services are usually funded. Check all that apply.**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CAC Waiver	1	1	1
CADI Waiver	1	2	4
County funds	1	2	4
DD Waiver	1	2	4
MA state plan home care services (SNV, PDN, HHA, Therapies, PCA, Mental Health)	1	1	2
Parents or family members	2	2	3
School systems	1	1	3
TBI Waiver	1	1	2
Other	0	0	2
Please specify in what other ways these services are funded.			
CCDTF			
Private resources, YMCA			

15. Please check the CAC Waiver services used to provide the services during non-school hours to youth with chemical health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	1	1	1
Extended Home Care Services	1	1	1
Respite	1	1	1
Other	0	0	0
Briefly describe Other services provided during non-school hours to youth with chemical health conditions in your county..			
0			

16. Please check the CADI Waiver services that are used to provide the services during non-school hours to youth with chemical health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	2	2	3
Extended Home Care Services	1	2	3
Independent Living Skills (ILS)	1	1	3
Respite	1	2	3
Other	0	1	1
Briefly describe Other services provided during non-school hours to youth with chemical health conditions in your county.			

- Assessment, treatment, activities, youth development

17. Please check the DD Waiver services that are used to provide the services during non-school hours to youth with chemical health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	1	2	3
Consumer Training and Education	1	2	3

Extended PCA	1	2	3
In-Home Family Support	1	2	2
Personal Support	2	3	4
Respite	2	3	4
Other	1	1	1

Briefly describe Other services provided during non-school hours to youth with chemical health conditions in your county.

- Limited mental and social health services

18. Please check the TBI Waiver services that are used to provide the services during non-school hours to youth with chemical health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	1	1	1
Extended Home Care Services	1	1	1
Independent Living Skills (ILS)	1	1	1
Respite	1	1	1
Other	0	0	0

Briefly describe Other services provided during non-school hours to youth with chemical health conditions in your county.

0

19. Briefly describe the services for youth with chemical health conditions during non-school hours. Please include information on the setting, ratio, supervision level, availability (hours and days) of the program and involvement with non-disabled peers.

- A residential placement is available for some kids with CD issues, otherwise, the Sober School promotes some activities outside school day.
- Local CD Provider available for Group Programming, our county has very low numbers participating, but Provider accommodates us.
- Outpatient chemical dependency counseling.
- Rule 25 assessments, in and out patient CD treatment
- Schools run groups, YMCA sponsors programs

20. Non-school hours are defined as the time the school is not responsible for the youth (e.g., after school, holidays, summer vacations, etc.). During non-school hours, to the best of your knowledge based on what you know or have heard:

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Does your county fund services during non-school hours for youth who have chronic health conditions?	17	20	21
Does your county have a way to identify youth with chronic health conditions who have a need for services during non-school hours?	20	23	24
Has your county identified youth who have chronic health conditions who have unmet needs for services during non-school hours?	12	12	13

21. What barriers exist to developing services during non-school hours for youth with chronic health conditions, if any?

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Lack of funding for the services	26	28	31
Lack of providers for the services	20	23	24
Lack of resources to develop the services	18	23	26
Other	3	4	5
None	1	0	0

Please describe the other barriers to developing services during non-school hours for youth with chronic health conditions.

- Identifying the youth that are needing services, finding appropriate service providers in a rural county, funding for services.
- Lack of outreach, funding, medical care, in home support
- No money. No providers. Or no contracts with the county. You asked Yes and no questions but the answer choices are not yes and no. Makes the survey frustrating.
- Program design; funding priorities; inadequate links to community; insufficient integration of department programs; lack of policy to address topic; financial constraints

22. Please indicate how these services are usually funded. Check all that apply.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CAC Waiver	12	14	14
CADI Waiver	14	17	17
County funds	9	11	12
DD Waiver	12	16	16
MA state plan home care services (SNV, PDN, HHA, Therapies, PCA, Mental Health)	15	18	19
Parents or family members	13	15	15
School systems	6	8	9
TBI Waiver	7	7	7
Other	5	5	5

Please specify in what other ways these services are funded.

- DD SILS, Family Support Grant, Children In Need Program, SWCIL, DRS, other programs as applicable.
- Family Support Grant
- Family Support Grant or Consumer Support Grant
- Non profit agencies, community support, grants, etc.

23. Please check the CAC Waiver services used to provide the services during non-school hours to youth with chronic health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	9	8	8
Extended Home Care Services	7	7	7
Respite	9	9	9
Other	1	3	3

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county..

- Supplies and Equipment, Foster Care Corporate

24. Please check the CADI Waiver services that are used to provide the services during non-school hours to youth with chronic health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	10	12	12
Extended Home Care Services	9	8	8
Independent Living Skills (ILS)	3	6	11
Respite	13	14	14
Other	3	3	3

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county.

- Behavioral supports

25. Please check the DD Waiver services that are used to provide the services during non-school hours to youth with chronic health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	5	6	7
Consumer Training and Education	2	3	4
Extended PCA	4	6	6
In-Home Family Support	5	8	9
Personal Support	4	6	6
Respite	7	8	9
Other	0	0	1

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county.

0

26. Please check the TBI Waiver services that are used to provide the services during non-school hours to youth with chronic health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	6	7	7
Extended Home Care Services	5	6	6
Independent Living Skills (ILS)	3	3	4
Respite	7	7	7
Other	2	2	2

Briefly describe Other services provided during non-school hours to youth with brain injuries in your county.

- Behavioral supports

27. Briefly describe the services for youth with chronic health conditions during non-school hours. Please include information on the setting, ratio, supervision level, availability (hours and days) of the program and involvement with non-disabled peers.

- After school programming
- Again; no formal program; individuals usually in receipt of respite care services; and generally speaking I do not like to have a provider; (nurse--RN or LPN) only provide care to two children during the same time period. Each case is individual as to the needs; depends upon how much other support the family is in receipt of; what they identify at being supportive without overwhelming.
- Home setting, corporate foster care, one to one ratio 24/7 paid and unpaid,
- in home services, 1:1
- One child is 4 years old and needs a stomach tube for feeding and oxygen for breathing. He is unable to walk. He needs 24 hours nursing. The other child is 4 years old. He has a PCA a few hours AM and PM. He has cerebral palsy and cannot swallow all foods. He cannot walk or use his hands well.
- One to one staffing through (ILS or IHFS)work with the child in the home or community setting on specific goals set up by the child's team. These services are usually used in the after school hours on weeknights. Respite is provided either in the child's home or licensed group home setting and is also one to one typically used on the weekends. CDCS has provided families with much more flexibility on who they hire as staff, when the service is provided, and where the service is provided. Parents supervise staff with CDCS and corporate providers supervise staff with traditional waived services. Most involvement with non-disabled peers outside of school time occurs with siblings and in the community, but is not structured to be peer time. Many of the children I work with also receive 1:1 PCA services in their home.
- PS or respite or in-home. Shared staffing if appropriate for person,1:1 when needed.
- Setting: home; ratio: 1:1, constant supervision; CAC - one client with 16 hours per day PDN and extended PDN are used to provide respite. Provider has difficulty covering all of hours approved and is inconsistent at times. Child on CADI utilizes PCA and again at times there is inconsistency in coverage due to lack of agency finding providers. DD waiver client is on CDCS and utilizes an older sister for part of personal care and she is not always consistently available. Have one client in rural area that is unable to get PDN or PCA as can't find providers to cover the area. Involvement with non-disabled peers usually doesn't happen. Other children use State Plan Services - either PDN or PCA. Again difficulty with consistency of services due to lack of agencies finding enough providers. Lack of funding for respite services.
- Social rec (for all ages) & rehab services for employment issues for older youth.
- These services are in limited availability especially for families slightly over the income guidelines. There is no safety net in place either.
- Waiver program options: self designed CDCS; ratio per assessed need and therefore variable. We need after school programs for disabled youth and I don't know of any.

28. **Non-school hours are defined as the time the school is not responsible for the youth (e.g., after school, holidays, summer vacations, etc.). During non-school hours, to the best of your knowledge based on what you know or have heard:**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 17
Does your county fund services during non-school hours for youth who have developmental disabilities?	32	38	41
Does your county have a way to identify youth with developmental disabilities who have a need for services during non-school hours?	40	50	54
Has your county identified youth with developmental disabilities who have unmet needs for services during non-school hours?	30	46	50

29. What barriers exist to developing services during non-school hours for youth with developmental disabilities, if any?

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Lack of funding for the services	41	54	64
Lack of providers for the services	30	43	46
Lack of resources to develop the services	35	48	52
Other	7	9	10
None	0	1	1

Please describe the other barriers to developing services during non-school hours for youth with developmental disabilities.

- Clients who have waivers may be able to access the two or three programs that are available - but often full. St. David's, for example, offers a program but it is expensive and a great distance from many of the families.
- Lack of integration with community and contract providers resources; insufficient provider-to-client contact at the community level(e.g., resource fairs); insufficient waiver funding; unequal waiver funding (haves vs. have nots);insufficient County funds; limited community resources; legislative policy; overmediation of delivery structures (too many program layers to a decision to fund); lack of well trained direct line staff. Lack of information re options for parent/family members.
- Parents may be reluctant to apply for Medical Assistance which funds services. Their reluctance is typically either due to financial reasons or lack of ability to complete the paperwork necessary to get the child on services.
- specific staff/support with languages other than English
- The need for Culturally/Linguistically appropriate services.
- The numbers of children who have this need are limited, making it not financially feasible for providers to develop services.
- This is a huge under funded need. The vast majority of our incoming clients will not receive a waiver due to lack of waiver funds. The Family Support Grant also has a wait list. Many families are using PCA or CSG to assist with this need, though PCA is not intended for this purpose and parents often have difficulty getting staff. Many families are not capable of managing the complexity of the CSG. This is a big burden on families with little ways of supporting this need.

30. Please indicate how these services are usually funded. Check all that apply.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CAC Waiver	6	9	10
CADI Waiver	14	21	24
County funds	17	21	24
DD Waiver	24	31	35
MA state plan home care services (SNV, PDN, HHA, Therapies, PCA, Mental Health)	23	28	29
Parents or family members	26	27	30
School systems	8	7	9
TBI Waiver	4	6	6
Other	5	7	8

Please specify in what other ways these services are funded.

- A non-profit rec center provides some services and some of that might be funded under waiver or county money; otherwise, all services are individualized and funded as per individual
- Family Support grant
- Family Support Grant
- Family Support Grant or Consumer Support Grant
- Family Support Grants
- SILS Services

31. Please check the CAC Waiver services used to provide the services during non-school hours to youth with developmental disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	8	8	9
Extended Home Care Services	6	6	8
Respite	8	8	10
Other	2	2	2

Briefly describe Other services provided during non-school hours to youth with developmental disabilities in your county..

- Family Support Grant, Respite and Recreation Grant, Case Management; Campership Funds; Volunteer and Mentorship Programs; Childcare Assistance; Emergency Assistance; Family Preservation Funds; Family Group Conferencing, and more
- We also use skills workers to go in during this time to work on programs.

32. Please check the CADI Waiver services that are used to provide the services during non-school hours to youth with developmental disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	11	18	18
Extended Home Care Services	9	9	11
Independent Living Skills (ILS)	5	12	18
Respite	17	21	22
Other	6	5	5

Briefly describe Other services provided during non-school hours to youth with developmental disabilities in your county.

- Behavior Wizards, adaptive equipment and supplies, training for caregivers
- CAC
- Consumer Support Grant
- homemaker, family counseling and training

33. Please check the DD Waiver services that are used to provide the services during non-school hours to youth with developmental disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	16	22	27
Consumer Training and Education	8	11	12
Extended PCA	19	23	26
In-Home Family Support	16	26	30
Personal Support	11	17	20

Respite	21	29	34
Other	1	2	2

Briefly describe Other services provided during non-school hours to youth with developmental disabilities in your county.

- Assistive technology, home modifications, center-based respite, consumer training, crisis respite, crisis related technical consults
- Supported Living Services for those that are in foster care.

34. Please check the TBI Waiver services that are used to provide the services during non-school hours to youth with developmental disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	5	5	5
Extended Home Care Services	4	4	4
Independent Living Skills (ILS)	1	2	5
Respite	5	6	5
Other	1	1	1

Briefly describe Other services provided during non-school hours to youth with developmental disabilities in your county.

- Assistive technology, augmentative aids, special non-MA covered durable equipment

35. Briefly describe the services for youth with developmental disabilities during non-school hours. Please include information on the setting, ratio, supervision level, availability (hours and days) of the program and involvement with non-disabled peers.

- 90% of youth served utilize respite or in home support for after school care for 2-4 hours.
- DD services provided through the DD Waiver include PCA services, IHFS, SLS, and respite (two on CDCS - one talked about prior, as has both DD and chronic health problem). Setting: home and community; supervision level: 1:1, availability: PCA - difficulty getting consistent coverage - lack of providers (often need before school, but unable to obtain), IHFS - we have a good agency who has been fairly successful in finding providers and they are often the ones who are working on goals that include involvement with non-disabled peers. However, do not have DD waivers for children birth thru 10 and some older ones due to lack of slots and waiver pool availability. PCA services through state plan is the main service available, but does not always meet the need due to lack of providers and times available (hard to get before school in the mornings.) Respite is usually not available, unless family can find someone and purchase through the Family Support Grant.
- Generally services are one to one with a paid adult. Sometimes Special Olympics is attended with other disabled peers. Integration into after school activities i.e. sports, or community education activities is only possible when the child is young. Transportation and supervision become a problem as the child gets older. The cost of gas has made it so PCA's and In Home staff are not encouraged to take children out into the community where mileage will need to be reimbursed.
- Home setting, corporate foster care, one to one ratio or one to four ratio.
- Horse therapy is available in our county and funded by county dollars or CDCS. We also have a provider who offers support and socialization groups for children.
- in home support, 1:1
- In Homes Services, PCA services, and respite-all have 1:1 ratio/supervision, and a wide range of availability. Contact with peers varies. Parents also fund a wide range of activities.
- IN-Home Family Services, respite and PCA
- In-home/community, one-to-one ratio, staff work under direction of supervisor, but the supervisor is not on-site, evenings on weekdays during the school year, morning/evening in summer - involvement with non-disabled peers in community
- Most of the school age kids have a respite program- may be one to one, up to one to four- some have PCA, one to one
- No formal programs; all individually based; respite is with a licensed or non licensed provider; other services are identified and contracted with an agency to provide the care.
- One provider has developed a 'life skills' program which incorporates 1 on 1 training with some group activities. It is in a 'home' in the country, completely equipped. They garden in the summer and social activities are 'normalized' and in the community. It is waiver funded for the most part, but some CDCS families also purchase time. It is 5 days/wk all summer - during the school year, hours after school and some weekends. A few providers provide intermittent 1 on 1 after school activities but most report that there is not enough money to warrant hiring staff.
- One to one staffing through (ILS or IHFS) work with the child in the home or community setting on specific goals set up by the child's team. These services are usually used in the after school hours on weeknights. Respite is provided either in the child's home or licensed group home setting and is also one to one typically used on the weekends. CDCS has provided families with much more flexibility on who they hire as staff, when the service is provided, and where the service is provided. Parents supervise staff with CDCS and corporate providers supervise staff with traditional waived services. Most involvement with non-disabled peers outside of school time occurs with siblings and in the community, but is not structured to be peer time. Many of the children I work with also receive 1:1 PCA services in their home.
- Only services are arranged by providers working with youth who have DD waiver. Staffing is 1:1 and only on service days.
- Parental pay 1:1, available 24/7 Respite care 1:4, all peers disabled, available some weekends throughout year or in camp settings for a week at a time
- Personal Care attendants, therapy, in home support, community support. These services are only for families who qualify and that can often be a limited number.
- Personal Support to assist consumers in accessing community settings in a rural county. Respite to do the same but also to provide a break to parents.

36. Non-school hours are defined as the time the school is not responsible for the youth (e.g., after school, holidays, summer vacations, etc.). During non-school hours, to the best of your knowledge based on what you know or have heard:

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Does your county fund services during non-school hours for youth who have mental health conditions?	16	22	23
Does your county have a way to identify youth with mental health conditions who have a need for services during non-school hours?	27	34	35
Has your county identified youth with mental health conditions who have unmet needs for services during non-school hours?	23	31	34

37. What barriers exist to developing services during non-school hours for youth with mental health conditions, if any?

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Lack of funding for the services	31	39	45
Lack of providers for the services	28	36	38
Lack of resources to develop the services	27	37	37
Other	3	4	5
None	1	1	0

Please describe the other barriers to developing services during non-school hours for youth with mental health conditions.

- Funding for mental health services has been reduced. We have clients that are both mentally ill and DD and there is nothing for them. We desperately need programs for students not in school that are affordable, within easy access or where transportation is provided, and that actually work.
- Lack of training of PCA's and ILS services with the severity of mental health issues.
- Parents resisting help
- The difficulty of the child's behaviors and needs. Some kids have very high needs and their are not providers out there that can deal with the increasingly intense behaviors and mental health issues that today kids are dealing with. Usually both parents work in order to make ends meet. There are transportation issues, supervising issues, and inability to sometimes pay for services.

38. Please indicate how these services are usually funded. Check all that apply.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CAC Waiver	4	4	4
CADI Waiver	10	15	16
County funds	11	17	16
DD Waiver	7	8	8
MA state plan home care services (SNV, PDN, HHA, Therapies, PCA, Mental Health)	16	22	20
Parents or family members	16	19	16
School systems	6	9	9
TBI Waiver	5	5	5
Other	4	6	6

Please specify in what other ways these services are funded.

- Adoption subsidy; children's mental health
- Community providers pick up the slack, families go into debt to get services, grants, non profits
- Family Support Grant or Consumer Support Grant.
- Lots of MA in-home services, and then we are fortunate to be part of a multi-county initiative that is doing some stuff

39. Please check the CAC Waiver services used to provide the services during non-school hours to youth with mental health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	3	3	3
Extended Home Care Services	4	4	4
Respite	3	4	4
Other	0	0	0

Briefly describe Other services provided during non-school hours to youth with mental health conditions in your county..

0

40. Please check the CADI Waiver services that are used to provide the services during non-school hours to youth with mental health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	10	11	13
Extended Home Care Services	8	8	8
Independent Living Skills (ILS)	6	8	9
Respite	9	11	12
Other	3	3	4

Briefly describe Other services provided during non-school hours to youth with mental health conditions in your county.

- Camps, PCA, ILS,
- Group home.
- Homemaker, family counseling and training

41. Please check the DD Waiver services that are used to provide the services during non-school hours to youth with mental health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	6	6	6
Consumer Training and Education	5	5	5
Extended PCA	7	7	7
In-Home Family Support	7	8	8
Personal Support	6	6	7
Respite	7	6	7
Other	1	1	1

Briefly describe Other services provided during non-school hours to youth with mental health conditions in your county.

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42. Please check the TBI Waiver services that are used to provide the services during non-school hours to youth with mental health conditions.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	3	4	4
Extended Home Care Services	1	2	3
Independent Living Skills (ILS)	1	2	2
Respite	3	4	4
Other	0	0	0

Briefly describe Other services provided during non-school hours to youth with mental health conditions in your county.

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43. Briefly describe the services youth with mental health conditions during non-school hours. Please include information on the setting, ratio, supervision level, availability (hours and days) of the program and involvement with non-disabled peers.

- Again - they are individualized based on the person.
- Again no formal programs; all individually based providers; or agencies providing care to that specific individual
- As noted earlier
- Crisis Mental Health Services, CMH Case Management, Psychiatric, Therapeutic, Mentoring,
- I know that during the summer, some parents receive flex funds (if their child meets requirements) to attend camps
- I would just be speaking with regard to children who have developmental delays in addition to mental health issues. One to one staffing through (ILS or IHFS)work with the child in the home or community setting on specific goals set up by the child's team. These services are usually used in the after school hours on weeknights. Respite is provided either in the child's home or licensed group home setting and is also one to one typically used on the weekends. CDCS has provided families with much more flexibility on who they hire as staff, when the service is provided, and where the service is provided. Parents supervise staff with CDCS and corporate providers supervise staff with traditional waived services. Most involvement with non-disabled peers outside of school time occurs with siblings and in the community, but is not structured to be peer time. Many of the children I work with also receive 1:1 PCA services in their home.
- ILS services and respite
- My knowledge is as a LTC waiver case manager. Youth may have mental health diagnosis/disability. Services arranged would be coordinated based on need and resources. Mental Health service provider would most likely coordinate some services. I am not aware of programs designed for youth with mental health needs for after school or non school days. I would need to consult to find resources. Currently most clients have 1:1 therapy and staffing supports - but not a "program".
- Not applicable to my current case mix
- One to one in home support. About 6 hours a week. Need out of home activities also.
- PCA services, after school programs through school
- Residential Treatment facilities, 24/7 supervision,
- Therapy, groups, classes, in home workers, community support workers. Children may be supported between 0-5 hours per week.
- There are no "formal" services or programs in this rural county. As a result of creative case planning with families we may use respite care, PCA, CTSS, family-based services (both skills building and therapy)and independent living skills services.
- Usually OT depends on the families ability and the support system that they have. Some have more support then others.

44. **Non-school hours are defined as the time the school is not responsible for the youth (e.g., after school, holidays, summer vacations, etc.). During non-school hours, to the best of your knowledge based on what you know or have heard:**

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
Does your county currently fund services during non-school hours for youth with physical disabilities?	20	23	25
Does your county have a way to identify youth with physical disabilities who have a need for services during non-school hours?	33	38	42
Has your county identified youth with physical disabilities who have unmet needs for services during non-school hours?	25	30	33

45. What barriers exist to developing services during non-school hours for youth with physical disabilities, if any?

	Ages 0 - 5	Ages 6 -	Ages 12 -
		11	21
Lack of funding for the services	34	37	42
Lack of providers for the services	30	35	36
Lack of resources to develop the services	26	32	34
Other	5	7	6
None	2	2	2

Please describe the other barriers to developing services during non-school hours for youth with physical disabilities.

- Again, the numbers of children in this category do not warrant the development of these services.
- County is not wanting to expand licensing of facilities because Counties are forced to reduce staff because of budget problems.
- don't know most of these kids, and then they may/may not qualify for any funding
- Identification, funding, parent outreach, services being in the community itself, etc. We must often rely on community support agencies to do the work of the county.
- Lack of cooperation from parents.

46. Please indicate how these services are usually funded. Check all that apply.

	Ages 0 - 5	Ages 6 -	Ages 12 -
		11	21
CAC Waiver	11	13	12
CADI Waiver	14	19	20
County funds	10	12	12
DD Waiver	13	17	19
MA state plan home care services (SNV, PDN, HHA, Therapies, PCA, Mental Health)	20	22	23
Parents or family members	17	17	18
School systems	8	8	8
TBI Waiver	5	7	7
Other	4	4	4

Please specify in what other ways these services are funded.

- Adoption Assistance funds assist with children attending Summer Camps
- Community support agencies, United Way, families, donations, community support from donors, etc.
- Family Support Grant or Consumer Support Grant.

47. Please check the CAC Waiver services used to provide the services during non-school hours to youth with physical disabilities.

	Ages 0 - 5	Ages 6 -	Ages 12 -
		11	21
CDCS	10	11	10
Extended Home Care Services	9	10	9
Respite	10	10	10
Other	1	1	1

Briefly describe Other services provided during non-school hours to youth with physical disabilities in your county..

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48. Please check the CADI Waiver services that are used to provide the services during non-school hours to youth with physical disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	11	15	15
Extended Home Care Services	12	13	14
Independent Living Skills (ILS)	8	12	13
Respite	16	17	16
Other	2	2	2

Briefly describe Other services provided during non-school hours to youth with physical disabilities in your county.

- Occupational therapy, services are often very limited and not for families who do not meet financial eligibility.

49. Please check the DD Waiver services that are used to provide the services during non-school hours to youth with physical disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	8	10	12
Consumer Training and Education	6	7	8
Extended PCA	11	14	14
In-Home Family Support	10	14	16
Personal Support	9	10	11
Respite	11	15	16
Other	0	0	0

Briefly describe Other services provided during non-school hours to youth with physical disabilities in your county.

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50. Please check the TBI Waiver services that are used to provide the services during non-school hours to youth with physical disabilities.

	Ages 0 - 5	Ages 6 - 11	Ages 12 - 21
CDCS	6	7	7
Extended Home Care Services	6	6	6
Independent Living Skills (ILS)	2	2	3
Respite	6	6	6
Other	0	0	0

Briefly describe Other services provided during non-school hours to youth with physical disabilities in your county.

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51. Briefly describe the services for youth with physical disabilities during non-school hours. Please include information on the setting, ratio, supervision level, availability (hours and days) of the program and involvement with non-disabled peers.

- 90% respite or in home support for youth ages 10-21
- Again all individually based providers providing respite care; otherwise agencies to provide pca/ extended pca; and other various services; no formal after school programs
- AT home help. 1 to 1 help. Community integration and recreation.
- In home support, 1:1
- In home worker, Occupational therapist, physical therapist, speech therapist. These services can range from 0-8 hours per week.
- In-home/community, one-to-one ratio, staff work under direction of supervisor, but the supervisor is not on-site, evenings on weekdays during the school year, morning/evening in summer - involvement with non-disabled peers in community
- One to one staffing through (ILS or IHFS)work with the child in the home or community setting on specific goals set up by the child's team. These services are usually used in the after school hours on weeknights. Respite is provided either in the child's home or licensed group home setting and is also one to one typically used on the weekends. CDCS has provided families with much more flexibility on who they hire as staff, when the service is provided, and where the service is provided. Parents supervise staff with CDCS and corporate providers supervise staff with traditional waived services. Most involvement with non-disabled peers outside of school time occurs with siblings and in the community, but is not structured to be peer time. Many of the children I work with also receive 1:1 PCA services in their home.
- PCA services in the home and PCA supervision. Lifeline services and transportation services.
- Respite services and Extended PCA
- Skills worker 1 to 1 usually a few hours a week. Respite Care is usually used on the weekend for care giver relief but sometimes the parents will take it during the week and do a night out. PCA usually covers the hours after school until parent comes home and sometimes mornings if the parent is not there and the child needs assistance getting dressed and ready to go. In Home Support is also just so many hours a week usually after school is out.
- Social rec programs that are specific to those w/ physical disabilities and some that are not-but depends on availability/openings. after school employment svcs through rehab services-again, depends on availability
- Those with physical disabilities have either co-existing developmental disabilities or chronic health problems and are already included in the former questions and answers.
- Usually PCA, one to one.

52. Please provide any additional information you would like us to have related to the youth needs assessment for your county.

- Because my area is working with the PCA program and waivers, there may be programs and services available in my county that I am not aware of.
- Budget cuts impact on services
- Clients without waivers have almost no options for services. Parents are finding that the TEFRA fees are so high that parents are planning to give up waived services because of the high costs. Parents are frustrated at the lack of safe services for their children especially children who are autistic, plus physically disabled or mentally ill.
- Families come to the county to provide them with resources that are paid for or free. There's no such resources, so we do not meet the needs for non-school services at all.
- Funding sources for after school activities.
- Hennepin County would work within the LTC or DD waiver programs as (CDCS) as funds allow. Families could use FSG, CSG or R&R (40 grants throughout all of DD in Hennepin) to purchase supports but no county funds are dedicated for this gap in service. Families may also use PCA hours, if the child does qualify, regardless of disability type, but it would be depending on availability of staffing.
- I believe the best thing that could be done is to use alcohol taxes to fund a FAS-FAE waiver. Neither Mental Health or DD services and programming plans address their need and the mix of populations leaves each group wanting and vulnerable.
- I believe there is a huge need for after school kid friendly resources for kids who no longer qualify for child care. After school kid friendly programming is an unmet need for vulnerable kids and this is when kids are getting into trouble.
- I completed the service--generalizations. I do not have the time to be very specific about my caseload and what each child/cac/dd or non waiver recipient may or may not have used for this area of need; but mostly identified the resources that generally we would look to as a means of support for this need. Lately I have had a number of queries re: day care for small children that have developmental; physical; or behavioral needs and not having day cares that are able and or willing to assist with this need. Day care centers and private providers are limited to numbers and most are not willing to provide care to an individual that requires more time and attention. I have attempted to be somewhat creative; suggesting that the parent attempt to have the pca accompany child to day care setting so child is being supported in that setting but yet able to gain some socialization with peers; support the provider in their care; etc. Also, some of our older youth do not have many options for them as most settings are for younger youth. Obviously not enough funding or waiver allocations for all that have needs. Most providers I have that are willing to provide direct care to these kids are most willing to work with our kids with physical and complex health care needs but most are not likely to work with those that have behavioral difficulties. Aware of lots of services to assist in meeting these needs; and get creative; but sometimes finding the person to provide the care is a challenge.
- I hope I have answered your questions correctly. When you referred to our county providing services, I answered as the county providing the services through waivers, state plan services and Family Support Grant and not county only funding. We do not have county only funding for any of the services. I answered questions also based on current ages of clients we are presently serving on the waivers and not how we would use the services through the waivers in general over the age groups. Our youngest client on the DD waiver is 11 years old. We do not have room in our DD waiver pool to add more children. Respite is a definite need in all the disability categories for those who do not have a waiver. I do not think that the FSG will be able to keep up with the need.
- I would suggest eliciting information from the families. While our assessment is intended to be broad, we often focus on what we can do (within the public program scope) rather than the unmet need for which there are no services. There are ongoing requests for respite - that is age appropriate, therapeutic and community based. I have limited knowledge about the available options in the community for youth with special needs/disabilities.
- I'm hoping our nursing office filled one out also because they handle all the other waivers we just have the DD one. I know some of the services they provide because we do have clients that are on those waivers but they may have had additional information.

