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DEPARTMENT OF
HUMAN SERVICES

Legislative Report

Supportive parenting services

Feasibility study and service delivery recommendations

Disability Services Division

February 2023

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Contents

I. Executive summary

This report summarizes a 2022 feasibility study of developing and providing supportive parenting services and providing adaptive parenting equipment to parents with disabilities[1] in Minnesota. The study was managed by the Department of Human Services (DHS) Disability Services Division (DSD) and conducted by Management Analysis and Development (MAD). The research process included:

- Identification of needs or challenges parents with disabilities face and that supportive parenting services and supports could address.
- Identification of existing services and supports that might partially address the identified needs and challenges of parents with disabilities.
- Development of recommendations on how existing services and supports could be modified to better address the identified needs and challenges of parents with disabilities—particularly, but not exclusively, through modifications to Minnesota's Medicaid state plan or federal waiver authorities.

The research approach prioritized the voices of parents with disabilities and their families. It drew additional insights from subject matter experts on DSD's current disability services and their counterparts in other states with Medicaid or waiver services for parents with disabilities, as well as research and professional literature on parenting with a disability.

Priority findings in this report emerged across two or more of the three types of sources described above. One type of finding suggests opportunities for specific services—some of which might be expansions of existing programs, others that might need entirely new services and still others that will require partnership beyond DSD or DHS. Another type of finding highlights specific considerations for service delivery, regardless of the service itself. This second type of finding likewise sometimes calls for a relatively simple recommitment to DSD's ongoing priorities and other times suggests a more substantial need for collaboration or departure from current practice.

The research identified 22 priority findings, which are noted in Table 1 below. Fifteen additional findings emerged from a single type of data source and are briefly discussed in the body of the report. Potential recommendations related to these additional findings appear in Appendix C.

Addressing such a wide range of priority findings will be a complex undertaking for DSD. For that reason, the overall recommendations of this report focus on creating conditions for implementing a large number of highly responsive service changes. They include:

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[1] In accordance with the legislative language that authorized this study, the phrases "parents with disabilities" or "parent with a disability" in this report typically refer to people eligible for either Medicaid or waiver services programs. However, some research findings suggest a more expansive definition could benefit some parents and their families.

- Formalizing DSD's authority to change or add federal home and community-based waiver services.
- Drafting new language for Minnesota's Medicaid state plan to expand non-waiver services or to parents who are not eligible for waiver services.
- Identifying future opportunities for service expansion, service changes or interagency collaboration.
- Securing the administrative and staff capacity to carry out the other recommendations.

Several findings in this report suggest opportunities for DSD to learn from or collaborate with other divisions at DHS, other state agencies and additional partners. Those relationships can and should be cultivated well in advance of DSD pursuing new or expanded services or service delivery that could have implications for the partners' own work.

Table 1: Summary of priority findings

Category	Expand or change current activity	New activity	In partnership with others
Service or support	• Support for household management • Education about child health and development • Education about parenting and caring for a child • Home modification, assistive technology	• Adaptive parenting equipment (including infant and baby care supports) • Emergency and non-emergency respite care • Education and support for entire family re: parenting with a disability • Opportunities for peer connection and support among parents with disabilities	• Mitigate economic challenges (income, employment, etc.) • Transportation and mobility support • Sex and sexuality education • Expand use of existing parent education
Consideration for service delivery	• Awareness of existing programs and services • Make it easier to access services • Navigation support for accessing and using services (for parent, for whole family)	• Role reversal / children as caregivers • Whole-family assessment and eligibility • Whole-family services • Available supports change as children grow (re-assessment)	• Affordable and accessible housing • Concerns about involvement with child protection • Importance of advocacy and self-advocacy skills for parents with disabilities

II. Legislation

The 2021 Minnesota Legislature directed the commissioner of human services to study the feasibility of developing and providing supportive parenting services and adaptive parenting equipment to parents with disabilities. The direction focuses on service delivery under the Medicaid state plan or federal waiver authorities and specifies the content of a report to the Legislature in 2023.

This report addresses the Legislature's charge to the commissioner. The text of the authorizing language is below:

Laws 2021, First Special Session, chapter 7, article 13, section 69

DIRECTION TO THE COMMISSIONER; SUPPORTIVE PARENTING SERVICES STUDY.

(a) The commissioner of human services shall:

(1) study the feasibility of developing and providing supportive parenting services and providing adaptive parenting equipment to parents with disabilities and disabling conditions under Medicaid state plan or waiver authorities; and

(2) submit a report to the chairs and ranking minority members of the legislative committees and divisions with jurisdiction over health and human services by February 15, 2023.

(b) The report must include:

(1) an evaluation and recommendation on eligibility and service design for supportive parenting services and adaptive parenting equipment;

(2) the estimated cost to the state of a supportive parenting service and reimbursement for adaptive parenting equipment;

(3) draft legislative language and recommended Medicaid state plan and waiver amendments required to implement supportive parenting services; and

(4) other information and recommendations that improve family-centered approaches to Medicaid service design and delivery.

EFFECTIVE DATE.

This section is effective upon federal approval of Minnesota's initial state spending plan as described in guidance issued by the Centers for Medicare and Medicaid Services for implementation of section 9817 of the federal American Rescue Plan Act of 2021. The commissioner of human services shall notify the revisor of statutes when federal approval is obtained.

III. Introduction

Background context

Existing policy environment

Disability advocates and others in Minnesota have expressed interest in supportive parenting services for several years. Bills related to the provision of supportive parenting services were previously introduced in the 2017, 2019 and 2021 legislative sessions.

One stated purpose underlying the previous bills was to prevent removal of a child from a parent with a disability solely because of the parent's disability. Nationally and internationally, children are disproportionately removed from parents with disabilities compared with parents without disabilities despite being no more likely to experience abuse or neglect.[2] While some states prevent a parent's disability status from being considered as the sole or determining factor of removal of a child, others are silent on the matter —including Minnesota. The legislative intent related to this topic is that supportive parenting services and adaptive parenting equipment will assist parents with disabilities in their child-rearing tasks and, absent any other indications of abuse or neglect, reduce their contact with the child protection system.

Language in the 2017, 2019 and 2021 bills focused on two specific areas: the eligibility of child rearing tasks for support from personal care assistance (PCA) services and the eligibility of adaptive equipment for parenting and child rearing tasks as allowable or reimbursable expenses for parents with disabilities who are eligible for PCA services. The previous bills would have created an advisory committee to consult with DHS on the development of a pilot project for these services, as well as administration of state-funded grants to PCA provider agencies to take on the staffing, training and operational challenge of offering a new set of services.

The final language authorizing supportive parenting services in the 2021 special session took a somewhat different form than previous versions. Rather than implementing and evaluating a grant-funded pilot, the commissioner was authorized to study the feasibility of providing supportive parenting services and adaptive parenting equipment under the state's Medicaid state plan or waiver authorities.

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[2] David McConnell and Gwynnyth Llewellyn, "Stereotypes, Parents with Intellectual Disability and Child Protection," Journal of Social Welfare and Family Law 24, no. 3 (2002): 297–317, http://dx.doi.org/10.1080/09649060210161294.

Existing services related to disability and parenting

Medicaid state plan and waiver authorities

Minnesota's Medicaid state plan is a written document that describes the state's Medicaid program, known as Medical Assistance (MA). It is not only a description, but also serves as a contract between the state and the federal government about how the state will administer MA, so the federal Centers for Medicare & Medicaid Services (CMS) can verify Minnesota is able to receive federal funds that match state investment in MA services. Criteria for MA eligibility are set by CMS and include factors such as income and financial assets, family size and disability and immigration status.[3] Policies about allowable expenses under MA are also set by CMS and create constraints that affect the recommendations included in this report.

DSD operates a number of MA programs developed for Minnesotans with disabilities who have needs that could be met in an institutional setting but prefer to receive services and supports in their home or community. These programs, sometimes called "waiver services," are intended to give states the flexibility to meet the needs of people with disabilities in community settings and to be responsive to needs as they are identified. MA waiver programs provide services above and beyond MA state plan services. Minnesota's waiver programs are collectively referred to in this report as home and community-based services (HCBS) waivers. Each HCBS waiver program has its own intended service population, eligibility criteria and allowable services. The state's Community-Based Services Manual describes the HCBS waiver programs most relevant to the present feasibility study:

- Brain Injury (BI) Waiver: For people with a traumatic, acquired or degenerative BI who require the level of care provided in a nursing facility that provides specialized services for people with BI or who require the level of care provided in a neurobehavioral hospital.
- Community Access for Disability Inclusion (CADI) Waiver: For people with disabilities who require the level of care provided in a nursing facility.
- Community Alternative Care (CAC) Waiver: For people who are chronically ill or medically fragile and require the level of care provided in a hospital.
- Developmental Disabilities (DD) Waiver: For people with developmental disabilities or related conditions who require the level of care provided in an intermediate care facility for persons with developmental disabilities (ICF/DD)[4].

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[3] "Medicaid Basics," Minnesota Department of Human Services, updated May 13, 2019, https://mn.gov/dhs/medicaid-matters/medicaid-minnesotacare-basics/medicaid-basics/.

[4] "Community-Based Services Manual (CBSM): Waiver and Alternative Care Programs Overview," Minnesota Department of Human Services, https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_000852.

Waiver services are authorized by waivers the state submits to CMS in order to provide services that are not typically provided as part of Medicaid coverage. Like the Medicaid state plan, Minnesota's waiver amendments serve as both program descriptions and contractual statements about how the state will administer waiver services. Both state plan and waiver amendments are submitted to CMS by DHS, then reviewed and approved by CMS.

Medical Assistance and waiver services are only some of the many offerings collectively known as Minnesota Health Care Programs (MHCP). These services each have their own constraints in terms of service populations, eligibility criteria and allowable expenses and activities. DHS' provider manual for MHCP providers discusses these additional programs and services in more detail.[5] People enrolled in Medical Assistance or HCBS waiver programs are often referred to as members of those programs.

Self-directed services

DHS offers several services either within or as alternatives to MA for people with disabilities to be self-directed in coordinating the services and supports they need. They include:

- Consumer-directed community supports (CDCS), which might include services and supports available through waiver services programs.
- Consumer Support Grant (CSG), a cash grant program that serves as an alternative path to Medicaid for securing home care services.
- Family Support Grant (FSG), a cash grant program intended for the parents of children with disabilities. It can support expenses that are not allowable under MA—but children who receive waiver services are not currently eligible for FSG.[6]

Personal care assistance (PCA) services are available to people enrolled in MHCP programs; participants might or might not be eligible for or enrolled in MA. They provide support with a person's activities of daily living, health-related tasks, instrumental activities of daily living (such as cooking, cleaning or transportation) and observation and redirection of behaviors. However, PCA services are explicitly limited to the enrolled and eligible person, not others in their family or their home.[7]

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[5] "Provider Manual: Health Care Programs and Services," Minnesota Department of Human Services, updated March 4, 2022, https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=ID_008922.

[6] "Family Support Grant," Minnesota Department of Human Services, updated June 13, 2019, https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/fsg.jsp.

[7] "PCA Services," Minnesota Department of Human Services, updated March 21, 2016, https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/pca/services.jsp.

Another existing service area is called Home Care Services. Home care services assist people with medical, health-related and day-to-day activities in their homes.. However, home care services eligibility is currently limited to needs that are deemed medically necessary for a person with a temporary or permanent disability.[8]

A final existing service area is called Equipment and Supplies. MHCP covers a variety of equipment and supplies purchased for a person to meet their disability-related needs.[9]

All of these existing services provide a degree of flexibility for people with disabilities and their families; they are currently tightly focused either on services an adult might need for themselves because of their own disability or that a parent might coordinate for their child with a disability. This feasibility study explored the space in between: services needed by a parent with a disability that might directly benefit their child, regardless of whether the child has a disability.

Parenting-related services

A larger universe of programs and services support Minnesotans who are parents regardless of their disability status. They address areas such as employment, housing, education or training, peer support, resource navigation, health care and financial assistance. Some are programs of state agencies, while others are operated by organizations in the private sector. Notably, the research team was able to identify very few supports or services that are intended to serve people with disabilities specifically in their capacity as parents. In the research findings below, this report will also discuss a persistent theme: that parents with disabilities face additional barriers to benefiting from parenting-related services.

The parenting-related services and organizations noted by interviewees included:

- Family-facing organizations for education such as Help Me Grow,[10] as well as more general educational programs such as Early Child and Family Education, Head Start and Early Head Start.

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[8] "Home Care Services," Minnesota Department of Human Services, updated March 21, 2016, https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/home-care.jsp.

[9] "Equipment and Supplies," Minnesota Health Care Programs Provider Manual, Revised: Nov. 22, 2022, https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_008993

[10] "Help Me Grow MN," Help Me Grow MN, https://helpmegrowmn.org/HMG/index.htm.

- Navigation supports such as the Help Me Connect program[11] for child development and community resources hubs[12] for school readiness.
- Peer state interviewees described programs for parents of children with disabilities, such as Parent to Parent USA[13] or the Washington State Fathers Network.[14]
- Parents said having an adult rehabilitative mental health services (ARMHS) worker willing to focus on their parenting—because being an effective parent was an important personal goal—would be extremely valuable to supporting their entire family.
- Peer support online, either via informal peer-to-peer communication or more formally organized online support groups.

Parenting and disability-related resources identified through the literature scan included resource guides for adaptive baby care, parenting equipment and assistive technology more generally. Several written guides (sometimes with related support networks) for parenting with a disability exist and at least one state has created an extensive resource list related to supporting parents with disabilities. For a complete listing of resources identified by the research team, refer to Appendix B.

Additional parenting-related services were documented in 2018 by the Minnesota Children's Cabinet in a resource guide titled *Minnesota Services and Supports for Families with Young Children*, prepared as part of the Early Childhood Systems Reform project.[15] They include services overseen by seven different state agencies, including DHS. More than two dozen programs administered by state agencies listed in the guide offer services that address needs such as parent education, child care, food and nutrition, employment and economic assistance and affordable housing. A selection of the programs discussed in the resource guide appears in a table in Appendix A.

The breadth of services and supports noted in the resource guide reflect both the complex needs parents might face in raising children and the complicated landscape of services that currently exists to serve parents and families. In the context of this feasibility study, describing this landscape serves two purposes:

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[11] "Help Me Connect," Help Me Connect, https://helpmeconnect.web.health.state.mn.us/HelpMeConnect/.

[12] "Local Community Resource Hubs," Minnesota Department of Education, https://education.mn.gov/MDE/dse/early/preschgr/local/.

[13] "Parent to Parent USA," Parent to Parent USA, updated Aug. 4, 2022, https://www.p2pusa.org/.

[14] "Washington State Fathers Network," Washington State Fathers Network, updated Aug. 1, 2022, https://fathersnetwork.org/.

[15] Minnesota Children's Cabinet. Minnesota Services and Supports for Families with Young Children. St. Paul, Minn.: Minnesota Children's Cabinet, January 2018. Available at https://mn.gov/mmb-stat/2-gen/2017-children-and-families-program-inventory.pdf.

- It suggests opportunities for referral, outreach and coordination among existing programs that might serve parents with disabilities.
- It illustrates the needs parents with disabilities expressed regarding navigation and resource facilitation, which are discussed in greater detail in the findings section of this report.

Feasibility study

At the direction of the Legislature, DHS completed a feasibility study to explore not only which supportive parenting services and adaptive parenting equipment are beneficial to parents with disabilities, but also which services and supports DHS is well situated to provide. DHS contracted with MAD to complete the feasibility study and prepare this report. The MAD research team developed key questions and methods intended to prioritize the voices of parents with disabilities in identifying needs for support, then applied policy and programmatic expertise within DHS to understand the feasibility of addressing various needs.

Research purpose

The research team identified the following topics to address in the feasibility study:

- Understand needs or challenges for parents with disabilities.
- Understand existing practices or resources parents use to address the needs and challenges.
- Identify opportunities for DHS to address the needs and challenges.
- Recommend implementation approaches and considerations for DHS's work.

Methods

The research team adopted a primarily qualitative approach to this feasibility study in order to document parents with disabilities' lived experiences and the detail of potential program or service models. A series of interviews were combined with information from a literature scan and subsequently validated and synthesized using facilitated group processes with DSD staff.

Literature scan

Researchers reviewed a wide variety of literature: peer-reviewed academic research, research summary publications, policy and advocacy briefs, resource publications such as equipment lists and program manuals, firsthand accounts of parenting with a disability and HCBS waiver amendments and spending plans for Minnesota and a number of other states.

Key informant interviews

The research team interviewed several subject matter experts within DSD—three individual interviews, plus additional discussion when invited to a standing meeting of subject matter experts—then validated initial findings from those rounds of interviews in conversation with a wider group of DSD subject matter experts.

Concurrently, researchers interviewed five program staff from peer states with supported parenting programs through HCBS waivers or other federal sources (e.g., as part of a state's spending plan). MAD identified peer state interviewees based on review of current HCBS waiver amendments[16] and proposed spending plans for a state's temporarily increased federal medical assistance percentage (FMAP) under the American Rescue Plan Act of 2021 (ARP).[17] Both sets of documents were submitted to CMS and were current and available for public review as of April 2022.

Interviewees manage programs in Washington, Arizona and Connecticut; additional parenting support services are underway or planned in North Dakota, Iowa, Oregon and Washington, D.C., but program staff contacts were unavailable for interviews.

Parent and family interviews

The research team interviewed 13 Minnesotans with lived experience relevant to supportive parenting. Interviewees included parents with disabilities, their spouses and their adult children, in addition to advocates and those who work with parents with disabilities. Some interviewees represented more than one of these roles (e.g., both a parent and an advocate).

Interviewees were recruited via snowball sampling and were purposefully recruited for maximum heterogeneity of experiences, rather than proportionate representation of Minnesotans with various disabilities. Because of this approach, the interview cohort represented a broad range of experiences in terms of the type of disability, lifelong or acquired disability, children of different ages (and with or without their own disabilities) and geographic locations.

Recommendation development process

The research team invited a group of DSD subject matter experts to convene in a series of two virtual meetings in September 2022 to digest the initial research findings and begin to develop recommendations. Based on discussions in those meetings, the DSD attendees identified:

- A set of guiding principles for how the state should offer supportive parenting services.
- The intended outcomes for parents and families of offering supportive parenting services.
- Prioritization of which parent needs could be met by DHS, what actions would be needed to implement supportive parenting services and which needs are already met by existing DSD programs and services or elsewhere.

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[16] A searchable listing of states' Medicaid waiver amendments is available at https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html.

[17] State spending plans and narratives for ARP investments into HCBS programs are available for review at https://www.medicaid.gov/medicaid/home-community-based-services/guidance/arp-section-9817-state-spending-plans-and-narratives-and-cms-approval-letters/index.html.

The research process resulted in detailed findings to inform the development of supportive parenting services.

IV. Research findings

The findings described here primarily focus on the needs, challenges and concerns identified in different data sources. Researchers also asked interview participants for additional information about existing resources to meet those needs and for their suggestions about implementation of services.

Some findings are distinct to one of the source types (the existing research literature, program experts and parents' and families' lived experiences), some to multiple sources and some to all sources. This report begins with findings mentioned most consistently across all source types because recurring mentions across sources validate the importance of those topics. The report continues with discussion of additional findings that were noted in one or two of the three types of sources.

Priority findings

Services and supports mentioned across all sources

The services and supports listed here arose most consistently across the entire research process, suggesting they are among the most pressing needs facing parents with disabilities and their families.

Support for household management

Several parent interviewees mentioned housekeeping tasks such as cleaning or tidying spaces, washing laundry, grocery shopping and cooking when asked about their families' needs. While these needs are currently addressed by home care services or PCA services for people with disabilities, they are restricted to support for the person enrolled in the service rather than other members of their family. Interviewees emphasized a desire for service to the entire family in these areas. Some parents with acquired disabilities expressed regret that their own children had taken on what they saw as more household management than was appropriate for them at a young age.

Household management or housekeeping support were among the services that were top of mind for some program expert interviewees, who noted that currently PCA or home care service providers are authorized to prepare food or wash clothes for the eligible parent, but not for their children—even if the actual labor (e.g., a single, shared load of laundry or a single meal) is identical. A desire for these services also recurs in the literature: research participants for McKeever et al., Shpigelman and Mercerat and Saias all mention them.

Home modifications, adaptive parenting equipment and assistive technology

Program expert interviewees mentioned assistive technology, adaptive parenting equipment and home modifications in general terms as supports for parents' independent caregiving. That is, the modification or equipment can allow a parent with a disability to manage parenting tasks unassisted by another person. The research team asked parent interviewees about parenting supports they currently use and several mentioned assistive technologies or adaptive equipment.

They noted some routinely available items, such as reminder alarms to help parents with a brain injury remember schedules and tasks. They also noted specialized or adapted equipment, such as a car seat specially adapted to be hitched to and pushed by a motorized wheelchair.

Assistive technology and adaptive equipment for parenting also emerged in the research literature. Discussions of home modification were more in-depth in the research literature than in interviews. In an article about mothers with physical disabilities, McKeever et al. note that while home modifications facilitate parenting, “those who received the greatest benefit from renovations were those who enjoyed [the benefits of long] housing tenure and of ownership. Most renter-mothers were not advantaged in this way.” Turning to adaptive parenting equipment, they note “the absence of commercially available adapted infant furniture and equipment had a profound influence on the amount of extra time, planning and labour required by mothers.”

To try to address this need, organizations such as Through the Looking Glass and the Idaho Assistive Technology Project have prepared resource lists and guidebooks about obtaining adaptive parenting equipment. The authors of the latter guide write, “Many parents with disabilities describe the need for equipment for carrying and transferring infants and toddlers. Parents with older children describe the need for technology and adaptive equipment to support their involvement in their children’s educational and recreational activities. Items that promote safety in child rearing are also extremely important to them. Home modifications that make a parent with disabilities more independent are critical to both the safety of the adult and child and the ease of parenting.”

Overall, the equipment and modifications address a wide range of needs and fall into a few distinct categories:

- Home modifications to increase independent mobility and thus a parent’s ability to complete tasks.
- Specialized items designed to support parenting tasks.
- Widely available tools used in particular ways to support parents’ needs.

As noted elsewhere in this report, there are currently meaningful differences in terms of cost, reimbursement or whether an expense is allowable between purchasing specialized equipment or technologies and adapting more widely available items for use by a parent with a disability.

Emergency and non-emergency respite care

Respite care is an example of a need that is both universal to all parents and particularly critical for parents with disabilities. When discussed in more informal settings, one might refer to this service as babysitting. Indeed, Lightfoot et al. write about the specific benefit of informal respite care because of the adaptability of care available to suit a parent’s needs. As they put it, “None of the parents referred to this type of child care as ‘respite care,’ which would be the term for it if it were a formal support, but rather described it as ‘caring for’ or ‘watching’ their children.”

Several parent interviewees acknowledged the mundane reality of simply needing a break from parenting sometimes. But they also noted that respite caregiving for their children is essential during times when they need to attend to their own physical or mental health. Such moments might be pre-planned, but parents described the greatest urgency around unexpected moments that range from days where a parent's fatigue or pain is particularly severe, all the way to emergency medical care or behavioral health crisis. In contrast with other needs such as personal care or housekeeping services, the emergent nature of this need makes it particularly difficult to organize with providers.

Peer connection and support

Parent interviewees spoke about the importance of peer-to-peer connection with other parents with disabilities. Sometimes these comments were indirect, such as references to how their volunteer or advocacy commitments bring them into contact with other parents to form important social bonds. Sometimes parents made more direct comments, expressing a desire for support groups or peer connections and a perception that none were available to them specifically in their role as parents with disabilities. Three parent interviewees focused on the importance of peer connection through maintaining social ties and friendships with peers, in order to combat the dual isolation that can occur with both disability and parenthood. Two others talked about peer connection specifically through the value of peer mentorship. They described the value of turning to a similarly situated peer for advice, support and—particularly for those with acquired disabilities—the value of seeing someone further along in their adjustment as a role model.

In one example from the literature, the National Council on Disability refers to a 2001 study by Conley-Jung and Olkin about mothers describing opportunities for parent education. "Parents who are blind or have low vision often try to parent according to 'sighted ways of functioning' when they do not have role models with similar disabilities. According to one mother, 'The kind of support one can get from other mothers with visual impairments is not available…in the sighted community.'"

Put differently, while parents reported only marginal benefit from sighted educators, they reported much greater benefit from connection to peers who were also parents with low vision or blindness. They not only learned about parenting skills and information, but were able to learn the specific, adaptive techniques that others had used to parent independently and that a sighted instructor would not necessarily know. This specific benefit suggests more general advantages to peer connection for parents with disabilities.

Indeed, other authors reinforce the value of peer support. Research subjects interviewed by Shpigelman noted that peer support confers both practical benefits (such as peer-to-peer learning) and emotional ones, since parents are able to share about and seek support for their shared experiences. The National Council on Disability's Rocking the Cradle report recognizes centers for independent living (CILs) as natural providers of peer support opportunities in general and suggests an opportunity for parenting-specific peer support through those organizations.

That report also recognizes the California-based organization as a model for peer connection among parents with disabilities, noting it "has developed a national parent-to-parent network as part of its national centers for parents with disabilities. The organization has also facilitated peer support groups for parents with diverse disabilities for 30 years. … A particularly successful group established [in 1999] has led to the design of a training module—Designing Support Groups for Parents with Intellectual Disabilities—to support replication elsewhere."

One interview with peer state program staff further emphasized this finding through discussion of an ongoing program—though it is not authorized or funded under a Medicaid state plan or waiver authority. In Connecticut, the Department of Developmental Services employs 10 adults with developmental or intellectual disabilities as part-time self advocate coordinators. The coordinators connect with and advocate for members (i.e., Medicaid enrollees) on topics based on member needs. Among other offerings, the coordinators offer trainings and peer support around parenting and healthy relationships that are separate from the state's Parenting Support waiver services.

Sex and sexuality education

While it was not a common theme, at least one source from each category strongly asserted the need for positive, comprehensive sex and sexuality education for people with disabilities before they become parents. Much like mentions of parent education among other findings below, some interviewees described sex education as an upstream strategy for helping people with lifelong disabilities intentionally consider whether being a parent is part of their vision for their future.

The National Council on Disability describes this need through the lens of inadequate health care. The Rocking the Cradle report notes that "because of the 'nonsexuality myth' harbored by many health care professionals about people with disabilities, women with disabilities often receive inadequate and inaccessible health care. Similarly, women with disabilities are less likely to receive information on contraception. One study found that only 19 percent of women with physical disabilities received sexuality counseling."

Considerations for service delivery mentioned across all sources

These findings should frame DHS's work to develop services and supports for parents with disabilities. They suggest not only factors in the use of services and supports, but also potential measures of their effectiveness.

Concerns about bias in child welfare and child custody proceedings

Multiple interviewees and the research literature noted concerns about the prevalence of parents with disabilities' involvement in the child welfare system solely on the basis of having a disability. Not only was this concern a driver of Minnesota's consideration of supportive parenting services, it also emerged strongly among both parent and program expert interviews and is a significant theme among researchers about parents with disabilities.

Most important, parents with disabilities disproportionately have their children removed from their physical custody.

Lightfoot and LaLiberte point out that an unconscious bias and subsequent discriminatory actions might sometimes be to blame, as attending to parental disability when considering termination of parental rights "can shift the focus from a parent's behavior to a parent's condition or diagnosis." They note that the traditional paradigm of child welfare "typically has viewed independent parenting as crucial," and "[p]arents have often been assessed based on whether they can independently be responsible for all aspects of caring for their child or children." But in practice, most parents (regardless of disability) use parental supports: "Formal supports that are typically used among North American parents include paid day care, housecleaning, paid tutoring or even take-out restaurants. Typical informal supports include grandparents providing a night out for parents (respite care), neighbors shoveling snow off the driveway of a new parent (chore services) or parents joining together for carpooling to soccer practice (transportation services)." Though supports for parents with disabilities are similar, they assert that a historical view of people with disabilities as "unfit to parent" casts parents with disabilities' potential dependence on supports in a negative light in child welfare decisions.

At their last reporting, the National Research Center for Parents with Disabilities documented 15 states with legislation expressly forbidding one of the following regarding a parent's disability (or some specific disabilities, especially blindness):

- Consideration of a parent's disability in child custody or removal.
- The use of a parent's disability as the sole factor in such cases.
- The inclusion of a parent's disability in such cases without a heightened burden of evidence documenting harm to the child(ren) because of the parent's disability.

Minnesota was not listed among the 15 states. As of today, however, Minnesota's child custody statute (Minnesota Statutes 2023, section 518.17) prohibits a parent's disability alone in determining the custody of a child.

Moreover, in child welfare or child custody proceedings, parents with disabilities sometimes do not have access to the accommodations they need to demonstrate their ability to parent with support—contrary to requirements under the Americans with Disabilities Act. As Shade articulates in a legal analysis of consideration of disability in the termination of parental rights, responsibility for creating and providing adaptive or modified supports to preserve family units falls generally to the state. In Minnesota, this is delegated to the responsible social services agency.

Also, when parents separate or divorce, one parent's disability status is also sometimes used against them in determining custody arrangements. Multiple parent interviewees reported this experience.

Given such a challenging legal or practical landscape, parents with disabilities might see themselves at much greater risk of losing custody of their child(ren) purely because of their disability status.

Several parent and program expert interviewees noted this perceived risk can make parents hesitant to take advantage of parenting-related services—particularly from public agencies—fearing that it might draw unwanted attention to their families from child welfare workers.

To address these concerns, DSD should engage early and often with relevant partners, especially the DHS Children and Family Services Administration.

The DHS divisions, other state agencies and other partners can work to provide both reassurance about and concrete mitigation and protection from these potential risks. Doing so will be an important factor in at least some parents' participation in supportive parenting services.

Navigation and assistance in accessing and using services

Parent and family interviewees identified pressing needs for help with accessing, enrolling in and navigating services and supports. They indicated that awareness of and access to existing services can seem deliberately difficult, leading to misconceptions about the motivations of DHS and other agencies. They also noted that such a support, like a case manager or service navigator, would need to focus on the needs of the whole family, rather than serving the person with a disability alone.

The literature, state subject matter experts and peer state interviewees echoed the need for supports to help parents with disabilities navigate the service system and get connected to existing services.

Case management

While most peer states' supportive parenting programs focus on parent education, training and skill development, Washington State's Parent Child Assistance Program (PCAP) is an example of an intensive case management program for pregnant and parenting people who have substance use disorders. This three-year intensive home visitation and case management program helps participating women with meeting their needs—whatever those needs are. Case managers in this program help participants reach their self-identified goals by supporting them with accessing services in the community, such as transportation, parent education and nutrition services.

Case management has existed as a separate, reimbursable class of MA since 1986. Eight types of DHS case management services each have different provider requirements and funding arrangements. Under one form, Minnesota's waiver, Alternative Care (AC) and Essential Community Supports (ECS) programs, case management is defined as "a service that provides people and their families with access to assessment, person-centered planning, referral, linkage, support plan monitoring, coordination and advocacy related to waiver services, resources and informal supports that are not necessarily funded through the waiver." People providing case management for these programs must be a public health nurse, registered nurse or social worker. People receiving case management as part of a waiver program must also be receiving another waiver service. Participants in the Developmental Disabilities (DD) Waiver must receive waiver case management and habilitation. Waiver, AC and ECS case management cannot duplicate other Minnesota state plan or other waiver services, such as initial determination and ongoing review of MA eligibility or disability certification nor determination of financial eligibility.

Human services professionals in Minnesota have been working to improve case management services for over two decades, most recently through case management redesign. Case management redesign aims to address the complexity of the system for case managers and for the people they support.

Across several legislative reports, it has been documented that case managers are burdened with administrative responsibilities, high caseloads and other barriers that affect service quality and outcomes. People receiving case management say they have limited choices of who provides their case management and might be receiving support from multiple case managers, of different case management types, along with care coordination; they have difficulty understanding what they might expect and rely upon from the service.

DHS case management subject matter experts request that any work to better address the needs of parents with disabilities that involves case management be done in collaboration with existing case management redesign efforts. The DSD staff who are currently involved in case management redesign are open to and excited about the possibilities of partnering on the supportive parenting work's next steps.

Service navigation

While case management can be an essential support for a person with a disability once they are enrolled in waiver services, interviewees indicated that learning about waiver services, determining eligibility and getting enrolled in the first place can be challenging. At those times, something like service navigation provides additional support.

Two examples of service navigation support in Minnesota already serve people with disabilities: the Disability Hub ("the Hub") and the Minnesota Brain Injury Alliance's (MBIA) Resource Facilitation. A third example is being piloted by the DHS HIV Supports Section for people served under the Ryan White CARE Act.

Disability Hub MN is a free statewide resource network for people with disabilities. It helps users navigate services. The Hub specializes in deep knowledge of benefits planning but can offer answers and connections to other resources on a wide variety of topics such as health, housing, employment, education and community involvement. The Hub's website says, "There's no such thing as a wrong question." People can reach help by phone, via online chat or through an online form. There are no eligibility requirements limiting who can contact the Hub with questions. If they consent, people who reach out to the Hub can have their contact information and a record of previous interactions with the Hub tracked, so that if they call back, for example, they don't have to repeat themselves. The Hub's level of service spans from answering a one-time question to continued follow-along support on a one-to-one basis. DHS staff ensure that the most up-to-date information about services and policy changes are communicated to the Hub. The Hub's website has additional tools and resources, including for family members of people with disabilities and professionals. One relatively new section of the website is intended especially for families. The Hub and DHS continue to seek feedback about how to make it as useful as possible.

While offering similar services as the Hub, the Minnesota Brain Injury Alliance (MBIA) Resource Facilitators proactively contact people who have been reported to have sustained a brain injury.

When hospitals, emergency rooms and urgent care facilities make a report to the Minnesota Department of Health (MDH), a registry collects that data and sends a letter asking if the affected person would like to be part of the resource facilitation program. A third-party entity shares that same information with the MBIA and a resource facilitator follows up by phone. If a person enrolls in resource facilitation, they are followed for two years, with quarterly outreach from a facilitator, plus the opportunity to reach out to their facilitator anytime. Resource facilitators are regionally based, with about 10 facilitators serving about 4,500 people per year. There is no eligibility requirement. Resource facilitators also receive cold calls from people such as county-based case managers, guardians and family members who need help connecting someone with a brain injury to services. The resource facilitation model allows for supports that extend to the whole family. For example, a spouse or family member might call because they need support as a caregiver and the resource facilitator can help get them connected to a support group.

A pilot effort by the DHS HIV Supports Section is another emerging approach to help connect eligible people to services, even if they are not yet enrolled in any programs. Based on residency and income level, people with HIV can receive services through the federally funded Ryan White program. One of the Ryan White services is medical case management. While the barrier to entry into Ryan White might seem low, decentralized eligibility for different programs and services can make it challenging to people to navigate. Because of this, as well as the needs of people with HIV affected by the recent outbreaks in Minnesota, DHS HIV Supports is piloting outreach case management services. This state grant-funded service’s only eligibility requirement is that a person is living with HIV. It allows case managers in this model to, in part, work to help clients enroll in Ryan White services via tasks such as ensuring documentation and paperwork are complete and providing follow-up to receive services. One early learning from this pilot is that the provider organization funded to do outreach case management has deep, long-standing relationships with clients, so it can feel difficult to “hand off” someone from their support to a Ryan White provider, especially because those hand-off points are especially vulnerable times when someone can fall out of care. Future service navigation in this might include “braiding” multiple funding sources to offer more flexible navigation services that would not necessarily end once a client officially enrolls in Ryan White services—a model that might also be applicable to service navigation for parents with disabilities.

Services and supports noted by parents and families and in the literature

The following topics were noted by parents and families and in the research literature, but less so by program experts. They warrant careful consideration by DSD in developing supportive parenting services.

Transportation and mobility

Parent interviewees noted two distinct transportation-related needs for their families. Transportation for adults with disabilities, such as paratransit services, can be challenging for parents with disabilities to use along with their children.

Some transit systems place limitations on the number of support people or guests that can accompany a rider with a disability: for example, a parent traveling with a PCA and one or more children may not be able to ride. Moreover, paratransit drivers are often unable to wait for riders to make return trips. This means a parent and their child might need to schedule and wait for two separate rides to accomplish even a simple errand independently.

Mentions of transportation in the existing research literature echoed discussion of parents with disabilities traveling with their young children. The National Council on Disability notes the same concerns that interviewees described and adds that in many paratransit agencies nationally, drivers are barred from assisting parents with their child in a car seat beyond getting it off the vehicle and onto the curb. This means parents with physical disabilities might be transported to a location, but might not be able to move the car seat from the curb into the destination.

Several parents with disabilities also described a desire for their older, school-aged children to have access to safe, affordable and convenient alternative transportation. These comments typically arose in discussion of parents' desire for their children to have typical childhood activities such as play dates, sleepovers or after-school and weekend enrichment activities even when the parent's own mobility is limited. They discussed being either occasionally or permanently unable to drive their children to and from these experiences.

There is much less emphasis on transportation for children independent of their parents with disabilities in the research literature. It arises somewhat in the context of participating in recreation and leisure activities as a family, a finding discussed in more detail below. McKeever et al. describe the effort necessary for some parents with disabilities to navigate their surroundings. The parents they interviewed sought to "provide the same levels of safety [as non-disabled parents] through the careful spatial and cognitive mapping of routes and routines. When travelling with young children, mothers charted alternate routes away from areas of heavy traffic. However, these pathways frequently involved more isolated areas and were generally the least direct routes to parks or shopping malls."

Mitigating economic challenges

Many parents face economic challenges. Many people with disabilities face economic challenges. Several parent interviewees stated clearly that parenting with a disability complicates and compounds the economic challenges a person might face.

Employment was often at the heart of these comments. A parent with a disability might feel a strong desire for economic independence through full-time employment that supports their family.

Some interviewees also noted that full-time employment would help them demonstrate to their children values such as self-sufficiency, persistence and resilience.

However, various barriers to full-time employment can amplify one another:

- Child care to make employment possible must be not only available and affordable, but also accessible to a parent with a disability (e.g., in an accessible facility, with staff willing to make accommodations for a parent's full participation in the program).
- Full-time work must not only pay a living wage, but also accommodate both parenthood (e.g., excused and paid time off to unexpectedly care for children out of school/child care) and disability (e.g., scheduling flexibility around appointments, pain or fatigue). Moreover, the nature of some disabilities simply makes full-time work difficult or impossible.
- Many people have the perception that increased income from employment might jeopardize benefits and services they or their family need, such as Medical Assistance, Social Security Disability benefits and other supports that have income or asset restrictions. For many people with disabilities, the cost of replacing these services privately would outweigh the increased income of full-time work and would reduce their family's economic security.
- People also might not be aware of work incentives that would let them keep benefits while they work or get benefits back quickly if they stop and are needed again, exacerbating concerns about people with disabilities being able to get needed benefits while they work.

The National Council on Disability echoes these concerns, using the Temporary Aid to Needy Families (TANF) program to illustrate the tension between a parent's ability to work and the risk of lost benefits. "Without appropriate family and work supports to overcome barriers to employment," the authors write, "parents with disabilities, especially single mothers, may be unable to comply with [TANF] regulations, resulting in a loss of benefits to their families. Advocates say that the work requirements do not specifically consider disabilities as a barrier to work. In addition, low-paying work and lack of job training programs for people with disabilities are common obstacles to employment and people with disabilities still face significant discrimination in the hiring process, further hindering their ability to comply with the work requirements."

In addition, the National Council on Disability also emphasizes the value of good benefits planning. In another report, a National Council on Disability committee "heard from workers, families and providers alike about how important benefit/work incentive counseling is to a successful transition into a competitive, integrated employment situation" and learned "that the transition was much more successful when the person had this counseling support, but some people were not aware of this valuable service."

Use of existing parent education services

Some interviewees said parents with disabilities would benefit from greater awareness of and involvement in existing parent education and training (such as Early Childhood Family Education, Head Start and Early Head Start and Family Home Visiting for parents of newborns).

They noted and the literature validated, that these programs are often accessible and inclusive but sometimes could do more work to reach and adapt to the needs of parents with disabilities.

This perspective is echoed in the National Council on Disability's report, specifically about Head Start and Early Head Start: the program "already provides many of the components necessary to serve parents with disabilities: outreach networks, access to educational specialists, individually tailored educational plans and close ties to a range of social services. In addition, [the] target population—children and families in poverty—is similar in many ways to families in which a parent has a disability: 'Both groups are parenting in compromised circumstances that often include low-income, unsafe housing, unemployment or underemployment and inadequate social networks.'"

Considerations for service delivery noted by parents and families and in the literature

Family-centeredness and whole-family support: services, eligibility and assessment

A family-centered approach

Multiple parent interviewees described their desires for supportive parenting services in terms of being "family-centered" or involving and considering their whole family. This idea builds on an existing paradigm within DHS of taking a person-centered approach to disability services—the idea that a person with a disability is a driver and an active participant in decisions about the care they receive and that the person's own goals, preferences and strengths are at the center of their service plan.

A family-centered approach works similarly and involves the perspectives not only of the person receiving services, but their family or other support system. It is characterized by trusting relationships with providers, individualized services and a focus on the well-being of the entire family unit. Service areas related to and reaching beyond disability services sometimes use this approach, including behavioral health, child welfare and economic self-sufficiency.

Service eligibility and parenthood

Beyond simply considering parenting activities as goals or elements of a service plan, several parents expressed a desire for program eligibility decisions to consider the demands of parenting in a person's life. These interviewees saw their needs for support as having added complexity because of the combination of their disability and their role as parents. For example, an adult who might not qualify for services based on their ability to care for themselves independently might have far greater difficulty (e.g., greater fatigue, greater cognitive load, greater mobility needs) because they are also parents or caregivers. Considering parenting as an instrumental activity of daily living not only opens the door to whole-family support, it also validates a person’s parenting role as a central and permanent part of their identity.

Attending to an entire family’s needs, rather than an individual adult with a disability, represents something of a paradigm shift.

As Lightfoot and LaLiberte note in discussing parents with intellectual or developmental disabilities, “although the definition of supports currently used in the AAIDD [American Association on Intellectual and Developmental Disabilities] manual is focused on individual functioning, the notion of parental supports broadens this focus to include an emphasis on family functioning, including the children of parents with disabilities. It makes little sense to evaluate or assess individual functioning or to develop supports for individual functioning when a person with a disability is a parent, because the parent–child relationship is a paramount part of a parent’s life.”

Whole-family services

Beyond discussions of eligibility and assessment, many of the parent interviewees also expressed a desire for supportive parenting services to wrap around the needs of their entire family. Examples emerged across several of the priority findings already described in this report, from training and education for family members to peer emotional support and transportation solutions for children of parents with disabilities. More than one interviewee put it succinctly: because a parent’s job is to care for their family, any services that support a child’s needs are also indirect supports for the parent. Program expert interviewees from Minnesota and from peer states echoed this sentiment, pointing out that a family’s stability depends on everyone’s needs being met to the greatest extent possible.

DHS is already developing ways to consider whole-family approaches to addressing human services needs. For example, the Economic Assistance and Employment Supports Division was a lead partner in the Minnesota 2-Gen Network, an initiative to support Minnesota families by advancing policies and practices to provide integrated, coordinated services “that improve outcomes for children and parents, together … in ways that are aligned and mutually reinforcing.”

Beyond reliance on intra- and interagency expertise in Minnesota, the Aspen Institute’s Ascend program is a resource in advancing this work. Ascend develops and disseminates two-generation approaches to “forge pathways to educational success and economic mobility for both children and the adults in their lives.” The program includes an extensive “2Gen Toolbox” searchable library of more than 300 research, resources, policy documents and case studies related to two-generation services.

Assessment and the family unit

Similarly, parent interviewees expressed a desire for state and county agencies to assess parents with disabilities for program eligibility through lenses that are not currently considered. Some discussed how the needs of the entire family unit should be factored into assessment for services, rather than considering a parent as though they are a person who is responsible only for their own needs. Several also highlighted the additional distinct needs or challenges a parent might face that are not always apparent when assessing someone’s capacity and needs solely in an individual context.

For example, a parent of an infant or toddler who has certain physical or mobility disabilities might be assessed as having the strength and dexterity to complete activities of daily living for themselves, but that assessment does not account for the additional bending or reaching demands they experience in caring for their child.

Medicaid state plan and waiver services might pose a challenging policy environment for the adoption of whole-family assessment or even assessment that explicitly considers the needs of family members beyond the MA member themselves. Agencies have used this approach in other areas of human services, however. For example, the University of Minnesota's Future Services Institute worked with Olmsted and Dakota counties to develop and pilot the Integrated Services Assessment tool in 2017. This tool brings a family-centered approach to assessment, allowing caseworkers and clients to articulate areas of need, strength and goals from the perspective of the entire family.

A second example from the Minnesota Department of Veterans Affairs suggests how assessment can attend to family needs more broadly. Veterans Affairs' flexibility is made possible in part by a less complex policy environment than that of Medicaid and waiver services. The agency provides rehabilitation services to veterans with a wide variety of acquired disabilities. Because of the breadth of peoples' potential needs, the person's own stated priorities or needs drive the intake and assessment process organically.

A wide variety of support services can then support the person as needed—including support for adaptive parenting techniques—without the closer attention to eligibility or allowable expenses as a person (and their providers) in Medicaid or waiver programs might need.

Moreover, a potentially ongoing relationship between a veteran and their Veterans Affairs providers means a person might have the time and space to seek support for what they perceive to be secondary concerns rather than focusing closely on a single concern in a handful of contact hours. Examples of the flexibility to consider parenting in Veterans Affairs' rehabilitation work appear in the Commission on Accreditation of Rehabilitation Facilities 2022 Medical Rehabilitation Standards Manual, which includes parenting both as a factor to consider in patient evaluation and an area of specialized services.

Much as DSD can take inspiration from or partner with family-centered experts in child welfare or behavioral health or whole-family service experts in the 2-Generation Policy Network, staff might be able to draw on peers in the Minnesota Department of Veteran Affairs or the University of Minnesota's Future Services Institute to help them rethink assessment for Medicaid state plan or waiver services.

Ongoing, evolving supports

As children (and their parents) grow and change, so will a parent's or family's service needs change. This finding might seem obvious, but it suggests an important mindset in supporting people through many years of parenting needs.

Parents' needs will necessarily vary over time based on several factors:

- The ages and changing needs of their child(ren) will inform what supports make sense for the family (such as the need for an adaptive crib vs. support navigating school parent-teacher conferences).
- A parent's own disability and needs might change over time as well and their need for supports might change, persist or end altogether—and new needs could arise again in the future.
- Finally, the wider landscape of support systems and resources available to a family can change over time. One parent interviewee spoke candidly about how she had lots of informal support from friends and family in the months after acquiring a disability, but much of that support faded over time and her young children were left with substantial caregiving responsibilities.

Children as caregivers

Several interviewees expressed concerns about what they called "role reversal," in which a child becomes a primary caregiver for their parent with a disability. The parents acquired disabilities when their children were elementary-aged and the children both took on household management duties that were inappropriate given the children's ages and also experienced the isolation of full-time caregiving. The experiences of these parents (and one now-adult child) left them with regret that the children did not have more support both as caregivers and as children needing support and care in their own right.

These interviewees described how additional home care services provided by paid professionals could have prevented their children from taking on too much of a household manager or caregiver role. Beyond caregiving concerns, they also noted that supports for a child's other needs—for their own peer connection and support as children of parents with disabilities, as well as opportunities to participate in typical childhood activities—were also critical.

On the other hand, research by McKeever et al. gently challenge this notion, finding "it was often the unsuitability of the home and community care services, rather than the nature of the mother's disability, which necessitated the suspect provision of personal and homemaking care by children. Mothers without spousal support and those who rented appeared to be at the highest risk of requiring problematic levels of assistance from their children." While "role reversal" experiences might not be universal ones, they do highlight that families with older children—not only infants or toddlers—could benefit from whole-family services for parents with disabilities.

Housing

Finding and securing housing that is affordable and meets the needs of both parents with disabilities and their children can be difficult. The National Council on Disability's report titled Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children discusses housing extensively in a chapter on supporting parents with disabilities.

Among other points, the report notes that sometimes a home suitable for children (e.g., in terms of the number of bedrooms, outdoor space, proximity to schools) might be neither affordable nor accessible to a parent with a disability. Other times, a parent who might qualify for subsidized rental housing might find their options either inaccessible or not suitable for their child(ren)'s needs. And a parent who might require supportive housing or other services, either permanently or temporarily, might not be able to live with their child(ren) in those settings. This latter point was echoed in the experiences of one parent interviewee.

Services, supports and considerations noted by program experts and in the literature

Parent education and training

Interviewees who are program experts spoke at much greater length about needs for parent education, training and skill development than did parents or families. These needs might be more top-of-mind for program experts than for parents with disabilities themselves, suggesting they might be lower priorities for parents. On the other hand, this emphasis among program experts might signal that education and training needs would be quick wins for changing service delivery—for example, as services that are already clearly allowable under existing CMS policies and in Minnesota's Medicaid state plan and waiver amendments.

The prevalence of training and education discussion was partly driven by the nature of most peer states' existing programs, which focus more on education and training for parents with intellectual or developmental disabilities. Several of the peer state interviewees manage waiver service programs in their states under which parenting-related education and training is an available service. Among peer state interviewees, there were two notable exceptions to this typical program structure, both of which are described elsewhere in this report in more detail:

- Washington state's Parent Child Assistance Program (PCAP) is a three-year, intensive and holistic home visitation and intensive case management program for pregnant and parenting women with substance use disorders.
- Connecticut's Self Advocate Coordinators program, discussed above, employs 10 adults with developmental or intellectual disabilities to support Medicaid and waiver members on a range of topics, including offering trainings and peer support around parenting and healthy relationships.

The value of parent education, especially for parents with intellectual or developmental disabilities, also appears in the literature. Saum's review of parenting with intellectual disabilities discusses training interventions, stating "It has been argued that training can improve the knowledge and skills of mothers in virtually all areas of parenting, with behavioral methods—such as modelling, verbal instructions, physical guidance, breaking tasks into smaller steps and using pictorial aids—being the most effective intervention in relation to acquiring practical and relationship skills." However, "there are some limitations to training programs which have been reported in the literature, particularly in relation to maintaining and generalizing taught skills."

These limitations include poor transfer between skills learned outside the home and applied in real-life settings and limited correlation between parents' knowledge gains and observed application of skills.

Advocacy and self-advocacy skills

Some parent interviewees spoke about the importance of self-advocacy as a person with a disability and participation in groups such as Self-Advocates Minnesota, to build skills and confidence around ensuring their own needs (and their families' needs) are met. Others spoke specifically about legislative advocacy training (such as the Governor's Council on Developmental Disabilities' Partners in Policymaking) as a source of not only skills and confidence, but also community and mentorship.

The research literature also illustrates a focus on self-advocacy that extends beyond the immediate needs of parents themselves. McKeever et al. give an example in the context of parents supporting their children's education. They write that in order to be actively involved at school, "most mothers channeled their children into the few accessible day cares or schools or requested what they referred to as 'special arrangements' by asking that the teacher meet them outside inaccessible classrooms for parent–teacher interviews. One mother successfully dealt with the same school board trustee at each of her son's transitions to elementary, middle and secondary schools in order to make the buildings wheelchair accessible. In the vast majority of cases, the responsibility to advocate and press for changes rested with the mothers themselves." Just as all parents sometimes must advocate for the needs of their children, sometimes parents with disabilities must also advocate for the accommodations needed to participate in their children's lives in community settings.

Additional findings

The research team identified the priority findings in the previous section based on the strength of recurring mentions across more than one type of data source. That is, they benefit from the added strength of research validity provided by data source triangulation. The findings in this section are categorized as additional, non-priority findings because they emerged from a single area of the research—from parent and family interviews, program expert interviews or the literature alone. Because they lack the heightened validity provided by appearing across multiple data sources, they are not discussed in detail among the main recommendations of the report. These additional findings are included here to offer a complete picture of the needs and challenges parents with disabilities and their families might encounter. A brief description of potential actions to address these non-priority findings appears in Appendix C.

Services and supports from parent and family interviews

Whole-family education

Some parent interviewees shared a distinct perspective on education and training needs. Rather than focus exclusively on the training or education needs of a parent with a disability, they suggested education and support for entire families.

The focus of this service would be to give a parent’s informal support system—grandparents, siblings, friends and even older children—insight into the experience of having a disability or being in a family with a person with a disability.

Considerations for service delivery from parent and family interviews

Outreach and communication

Challenges with access to existing services are noted elsewhere in this report. But at least one parent also noted a striking perception: a belief that some services or strategies for accessing them are deliberately hard to learn about and access or even kept “secret” to limit enrollment. This interviewee and others urged DSD to ensure robust, proactive outreach and communication about any future services. Countering this negative perception, no matter how prevalent, will be important to ensuring the success of supportive parenting services.

Tailoring services to needs

Parents noted the need for services to be tailored to an individual parent’s or family’s needs, rather than a standardized service model. They noted this especially in discussions of parent education and training services. In those cases, a one-size-fits-all curriculum risks missing a parent’s educational needs because each family has different needs. Moreover, education services that are not customized risk being deeply insulting to parents, seeming ableist or presumptive about a parent’s abilities based solely on their disability.

Services and supports from the literature

Some needs or challenges did not arise (or were mentioned only infrequently) in interviews with parents or program experts but were more strongly indicated in the literature scan. In particular, many of the topics listed below were important findings from peer-reviewed research that focused on gathering and synthesizing a wider spectrum of parents with disabilities’ lived experiences.

Health care

The National Council on Disability’s report, Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children, mentions shortcomings in sexual health care for people with disabilities, discussed elsewhere in this report. The authors note that health care providers often do not discuss contraception—and that while contraceptives are generally covered under Medicaid state plans, most states “do not provide any further preconception care” that would support parents-to-be with disabilities. In making this assertion, the Rocking the Cradle authors point to a 2009 survey of states’ family planning-related Medicaid services by the Kaiser Family Foundation. That report defines and summarizes the state of preconception care under Medicaid in this way: “Among [preconception care] services are clinical exams, sexual health education and counseling, as well as infertility services.”

Medicaid recognizes family planning, but not preconception care services, as a defined category of covered services. With that distinction, “only a handful of states include many of the elements of preconception care as a 90% matched family planning service. While 26 of the responding states cover preconception counseling, only seven states routinely consider it as a family planning service, in contrast to contraceptive counseling (29 states and DC) and reproductive health education (20 states).”

Mercerat and Saias interviewed parents about their experiences with pre-pregnancy, pregnancy, delivery and postnatal care. During pregnancy and delivery, one of the central themes was being “disappointed by the lack of knowledge and experience of their medical team” at navigating care, especially for a pregnant person with a disability. Some interviewees from that study also noted providers’ inflexibility in making accommodations that would support pregnancy and delivery. In particular their study highlighted the importance of planning for both general and local anesthesia during delivery—and the importance of medical providers’ competency regarding the nuances of anesthesia and obstetrics for people with disabilities. Mercerat and Saias emphasize that pregnant people, their medical team and their anesthesia team should make plans for anesthesia together as “a crucial step in decreasing stress” during delivery.

Leisure and recreation

Research on parents with disabilities includes observations about family recreation and leisure experiences. Findings tend to address two main points: the desire for support in participating in family leisure activities (as in Mercerat and Saias), and the desire for more recreational opportunities that are accessible for parents with disabilities and their children to do together, particularly in outdoor settings (as in Shpigelman).

Moreover, the National Council on Disability notes that “families headed by parents with intellectual disabilities tend to be less affluent and more isolated. As a result, the community connections and discretionary income necessary to create memory-making family trips, outings and recreation are often limited or nonexistent.”

Considerations for service delivery from the literature

Informal support

Multiple sources in the literature discussed various informal social, emotional, practical or educational sources of support that are often provided by a parent’s network of family and friends. These informal supports included such things as advice or emotional support, as well as more practical supports such as respite care or serving as a resource to learn parenting skills.

The informal nature of these supports—rather than, for example, being coordinated through a human service agency—was described as a strength in several articles. As Lightfoot, LaLiberte and Cho note, parents expressed a strong preference for informal supports and characterized formal ones as “confusing and overwhelming [and] much less likely to meet their needs.”

Parents in the studies described informal supports as attractive because of the ability to access them on an ad hoc, as-needed basis, typically without cost and without advance planning or authorization and without navigating formal programs and systems.

Training or education for providers and policymakers

Program experts and, to a lesser extent, parents themselves, made comments about education and training for parents with disabilities. But some researchers highlighted a different need in their work: gaps in education about parenting with a disability specifically for providers and policymakers to better inform their work. Powell et al. note this among their recommendations, stating that better knowledge about adaptive parenting strategies would likely improve their ability to design and deliver effective services.

Infant and baby care supports

While several parents discussed assistive technologies or home modifications that support their parenting, needs for adaptive parenting equipment for infant care (e.g., for holding, feeding, carrying) emerged to a lesser degree. They were described more thoroughly in the literature. The two most robust documents available are both resource guides. One, a handbook titled Assistive Technology for Parents with Disabilities, was published by the Idaho Assistive Technology Project in 2003. It describes a selection of potential assistive technology for parents with various disabilities and needs, then advises on how to select and acquire the desired assistive technology. Another, published by the organization Through the Looking Glass, is a simple resource list of baby care equipment—some is specialized or adaptive, while some can be used by any parent. The list, last updated in 2016, describes where parents can purchase the item (typically, they are available from non-specialty vendors), the pros and cons of use and the types of physical or sensory limitations an item might support.

Needs and challenges identified in program expert interviews

In general, peer state interviewees spoke at more length than DSD interviewees about parent education needs, families' basic or economic needs, navigation or case management needs and parents' peer connection or support needs. Additional findings from both peer state and DSD interviews included:

Food and nutrition

Discussion in some program expert interviews took a holistic view of parents with disabilities' needs and well-being. In those interviews, the expressed needs and challenges ranged from specific supports for parenting tasks to a more general view of families' basic needs. Those comments typically included access to affordable, nutritious food among other needs. Similarly, while no parent interviews noted food and nutrition as a distinct challenge, it emerged for some parents when discussing their overall employment or financial challenges.

Request accommodations

Some parent interviewees expressed a need for accommodations in navigating parenthood and the literature describes organizations' and community members' obligations to provide accommodation. But only program experts highlighted a need for greater awareness among parents with disabilities about when and how to request accommodations—and that they are able to do so when it comes to their parenting tasks.

Education on healthy relationships, boundaries and social cues

One program expert interviewee expanded on the typical scope of parent education and training (e.g., child care, child development) in a distinct way. For parents with intellectual or developmental disabilities in particular, they noted that education about healthy relationships, boundaries and social cues can fill in important gaps about how to engage with others.

Before parenthood, these skills could reinforce sex and sexuality education, given that the state's Olmstead Prevention of Abuse and Neglect Specialty Committee for the Olmstead Subcabinet reported that adults with intellectual or developmental disabilities are seven times as likely as people without disabilities to be victims of sexual violence and roughly two-thirds of violence committed against people with disabilities is perpetrated by people they know.

And once people with disabilities become parents, these same skills can be applied to raising children. For example, they might help parents know how to set and enforce appropriate boundaries around a child's behavior. They also might equip parents to model healthy relationships and read social cues, helping them pass the skills along to their child(ren).

Positive behavior support

One interviewee noted that similar services DSD currently provides to adults and children with disabilities around positive behavior support could be beneficial in a parenting context. That is, the range of positive behaviors supported by providers could be expanded to include parenting-specific behaviors (such as completion of caregiving tasks, appropriate management of frustrations, etc.).

Behavioral health services

Similarly, one program expert interviewee noted that ensuring parents with disabilities have consistent access to behavioral health services is one way to provide parenting support. This might be true of parents whose disabilities are related to behavioral health. It might also be true of parents with other disabilities, but for whom behavioral health services would be helpful in managing the challenges of parenting with a disability.

Implementation insights from peer state interviews

Peer state interviewees noted opportunities around not only services (such as education and training) and supports (such as home modifications or assistive technology), but also service coordination across other programs or agencies. They shared many, highly detailed thoughts about program implementation based on their own experiences—they included the importance of role clarity among partners, program outreach and recruitment ideas and considerations about funding sources and program eligibility.

They shared lessons learned from their own experiences developing or managing programs and expanded service offerings. Comments from peer states offer a variety of insights, though they might not be applicable to every new or expanded service and support that DSD implements.

Clarity about roles and responsibilities among potential partners

- Clearly identify what supportive parenting services should be provided under MA or waiver services and what might instead be provided or funded by other partners (e.g., school or family education programs). Consider creating memoranda of understanding with interagency partners as appropriate.
- Similarly, consider roles of Medicaid and state dollars in funding the services. This has both fiscal and eligibility implications: will the service(s) be available to people with private insurance, rather than MA eligible? Are there any planned expenses that would conflict with CMS requirements?
- Ensure a shared understanding of agencies' and partners' roles in implementing services and supports. For example, would parent education through home visitation be implemented by Early Head Start providers, other family home visiting program models or others?
- As part of clarifying roles, remember to consider the potential roles of not only state agencies, but also counties and private organizations.

Support providers and partners in expanding services and supports

- Build capacity for parenting supports by allocating startup funding using state dollars for providers to invest in expanded hiring and training (for example, allowing behavior support specialists to incorporate training on parenting-related behaviors). Make providers' use of these funds a condition of being able to seek Medicaid reimbursement for supportive parenting services.
- Make plans for recruiting and retaining supportive parenting service providers across state.
- Make plans for outreach and communication to make partner organizations aware of the new or expanded services and supports that are available to their client populations.
- Educate individual case managers about the new or expanded services and supports that are available to their clients.

- If new services are developed that have large administrative needs, consider working with an external program manager that can invest time in training, monitoring and ensuring fidelity of the program model.

Critically consider eligibility and enrollment

- Because some parents with disabilities also have children with disabilities, consider both a parent's and child's eligibility for MA in determining eligibility for parenting-related services.
- Avoid setting eligibility criteria that might exclude some parents with disabilities who would benefit from the services, such as a maximum IQ (for parents with intellectual or developmental disabilities).
- In several peer states, participation in parenting services is lower than expected: Make it easy for clients to opt in and use supportive parenting services.
- Note that low participation might suggest a different approach is needed: One peer state's HCBS waiver program for parenting support is underutilized relative to a more informal, peer support service provided by the same agency.

Let form follow function

- Consider what needs will be addressed and let that drive program structure: for example, if connection and informal support are most important, should they be addressed through a waiver service? Alternately, if the need is to fill in gaps in parenting equipment or education for parents who lack informal supports, a waiver service might be a strong fit.
- Balance the customization of services needed to respond to families' diverse needs with the consistency of a cohesive service model.
- Over time, building an evidence base for the service model(s) is helpful in sustaining support.
- Consider the benefits and drawbacks of offering meetings, visits and other interactions via virtual platforms.
- Plan for supporting clients with limited English proficiency throughout enrollment in and use of supportive parenting services. Consider strategies such as providing translated documents and offering phone or in-person language interpretation.
- Remain open to ongoing state investments: for example, one peer state uses general fund dollars to employ people with disabilities as peer advocates and coordinators, addressing topics including but not limited to parenting.

Questions and considerations for planning service delivery

The research process highlighted several critical questions to consider in planning for supportive parenting services. The answers to these questions provided important framing for the recommendations in this report.

What needs should the new service(s) address?

Some needs that emerged in the research findings—such as the availability of affordable housing—are beyond DHS' purview altogether and thus a poor fit for the scope of the present work. However, these needs and services might suggest future opportunities for interagency collaboration or partnership with private and nonprofit sector organizations. Similarly, some needs might already be addressed by DHS, suggesting that additional services are not needed but additional outreach or communications efforts might be in order.

Should supportive parenting services be offered under the Medicaid state plan, waiver authority or elsewhere?

The policy and funding constraints (i.e., allowable expense) of each program area play an important role in dictating whether various services can be offered in any given area or even the particular scope of services that can be offered. For example, waiver services are intended to cover only equipment and services that are not otherwise allowable under the overall state plan. This means the research team and DHS program and policy staff have closely reviewed the proposed services in this report and determined whether they are allowable in various programs. Those determinations are reflected in the recommendations section below.

A related consideration might affect how specific services will be offered in the future: DHS is already in the process of making changes to service delivery, such as Waiver Reimagine and the transition from PCA services and the Community Support Grant to Community First Services and Supports. These changes are likely to overlap with the delivery of supportive parenting services and should inform how DHS creates or expands services for parents with disabilities.

Another, more specific example illustrates the granular detail of preparing for changes to service delivery: waiver services cannot cover an item that is for "recreational or diversional" purposes. A specially designed stroller might be considered "recreational" in nature under this policy, but an adaptation to a conventional stroller—necessary in order to make it functional for a parent because of their disability—would be an allowable expense. Even if the end result of an adaptive stroller is the same, the path to obtaining the equipment is different. This report recommends expanded support for navigation of both existing and new services, in part to help members and their families identify the simplest allowable path to the services and supports they need.

Finally, it is possible that one or more of the services and supports named in this report would be equally effective or even more effective, if implemented outside the Medicaid state plan or waiver amendments. Where possible, this report identifies other existing services that could be expanded or changed to incorporate the needs of parents with disabilities. These existing service changes often, but not always, suggest opportunities for partnership between DSD and other entities. The recommendations in this report are organized by complexity of the changes needed to adopt them: from those that might involve minor changes to allowable expenses in existing waiver services, to new services offerings, to complex interagency relationships.

Defining and implementing a family-centered approach to supportive parenting services

Mentions of parent-centered or family-centered design and services recurred throughout the literature and interviews with parents and family members. Interviewees did not always use the phrase “family-centered” but did describe a need for assessment, eligibility and service delivery to consider an entire family unit as the entity in need of and benefiting from services, rather than focusing solely on the parent with a disability as though they are an independent person. When DSD staff considered the notion of family-centeredness as part of developing recommendations for this report, the concept resonated immediately and positively.

Despite that emphasis from parents and DSD’s enthusiasm, designing services that are responsive to the entire family of a parent with a disability might be a departure from how DHS typically designs and delivers services. It also could represent a substantial shift in how DHS determines eligibility for services, the scope of supportive parenting services and more.

What is the scope of the potential service population? Which Minnesotans should be eligible for supportive parenting services?

Size of the potential service population

According to the U.S. Census Bureau’s American Community Survey 2020 five-year estimate (ACS), there were 2,961 people in Minnesota between the ages of 18 and 64 who have any disability and have one or more children aged 0–17 who are related to them and living in their household. Of those, an estimated 854 people have at least one child living with them under the age of 6.

Because ACS respondents self-report having any disabilities (which are described in the survey as “self-care difficulty,” “hearing difficulty,” “vision difficulty,” “independent living difficulty,” “ambulatory difficulty,” or “cognitive difficulty”), the Medicaid-eligible and waiver-eligible populations are likely smaller. As a proxy for this smaller population size, consider that the 2020 ACS estimated there were 16,845 Minnesotans aged 18–64 reporting any disability in 2020, while DHS internal reporting showed only 5,136 Minnesotans of those ages receiving personal care assistant services in SFY2021.

Factors affecting potential eligibility

Several other questions about who is eligible for supportive parenting services must be resolved, including:

- Should individual capacity or need determine eligibility or should (and could) the needs of an entire family unit be taken into account?
- Should families with minor children of any age (i.e., birth to 18) be eligible or only those with children of a certain age (e.g., birth to 5)?

- Should the service population include parents with disabilities who have lost or are at risk of losing physical or legal custody of their children, but might have children in their home some of the time or regain custody in the future?
- When considering supportive parenting education, training or peer support services:
    - Should people with disabilities who are interested in or exploring becoming a parent be eligible?
    - Should a person with a disability who is pregnant or expecting placement of a child be eligible?
    - Should supportive parenting services include education or discussion about human sexuality, pregnancy and parenting with people with disabilities before they become parents?

Parent interviewees also described how some of the needs and challenges parents with disabilities face are things that all parents experience, while others are magnified or experienced differently for parents with disabilities. Some challenges—especially navigating health care, employment, housing, human services systems, legal or child welfare systems and educational systems—can be amplified when a parent needs to navigate them alongside their disability.

VI. Recommendations

In light of the variety and complexity inherent to the research findings, the central recommendation of this report is to ensure adequate state statutory and federal authority to implement service changes in a variety of ways. In addition, state spending authority may be needed to implement new service design. A more detailed discussion of potential service changes appears below among additional recommendations. Still other potential service opportunities related to non-priority findings appear in Appendix C but are not the focus of this report's recommendations.

Some of the additional recommendations focus on changes to existing service delivery, some on the development of entirely new services and others on intra- and interagency collaboration. This section also outlines strategies to make DHS's overall service delivery more responsive to the needs of parents with disabilities, even when those strategies extend beyond the scope of any one service. For a summary of the priority findings that form the basis of the recommendations, please see Table 1 on Page 5 of this report.

Scope of supportive parenting services

Broadly, offering supportive parenting services and adaptive parenting equipment will mean expanding the scope of the state's existing Medicaid state plan and waiver plans. Depending on additional actions the legislature may authorize, it could mean expanding services or deepening interagency relationships in other areas.

In the short to medium term, the research team recommended four changes to prepare for expanded service delivery:

- Formalize DHS's authority to change or add waiver services, in order to be flexible and responsive in meeting the diverse needs of parents with disabilities.
- Draft new language for Minnesota's Medicaid state plan to expand supportive parenting services to parents with disabilities and their families who might be MA members but not eligible for waiver services.
- Identify future opportunities for service expansion, changes to service delivery or interagency collaboration to address parents with disabilities' needs and challenges that cannot be fully addressed under the Medicaid state plan or waiver authority.
- Secure the administrative and staff capacity to carry out the changes above and develop detailed implementation of the preceding recommendations.

Service eligibility

In order to determine costs for the expanded services, it is critical to determine who should be eligible to participate and which services and supports are available to which populations.

Eligible families should be those in which a parent with a disability has a minor child at least some of the time.

Within the scope of this study a “parent with a disability” includes people eligible for either MA enrollment or HCBS waiver services because of their disability. This includes parents with disabilities who might have shared custody of their child(ren) and parents who might be working to retain or regain custody of their child(ren). The research team recommends including parents of any children aged birth to 17, rather than limiting eligibility to families with only young children.

In the longer term, DHS might wish to adopt a whole-family approach to not only service delivery, but assessment and eligibility. This approach would be a departure from current DHS practice; it is discussed in the findings above and included among the service design recommendations below. Adopting such an approach could serve to either expand or contract the eligible service population for supportive parenting services and adaptive parenting equipment. It also might change or expand the working definition of “parents with disabilities” used in this report.

Service design: changing approaches to service delivery

A number of the potential actions described below address not which services should be delivered, but how DHS and its partners and providers should do so. While these recommendations are not directly tied to the Medicaid state plan or waiver authority, they have important implications for how expanded services could be implemented. Potential changes to service delivery suggest a re-commitment to current practices in some regards and larger departures from DHS’s current systems in others.

- Expand DHS’s understanding of eligibility, assessment and service delivery for parents with disabilities to include the needs of an entire family in decision-making. This would constitute a large, complex and long-term shift. It was also one of the service design considerations expressed most strongly by parents and their families. By way of illustration, these changes could look like:
    - Revising the MnCHOICES Assessment and Support Plan applications to factor in not only a person’s own functional capacity, but also the specific physical, cognitive and emotional demands of their parenting.
    - Changing the eligibility for some services that currently support parents of children with disabilities, but that could also benefit parents who themselves have a disability.
    - Coordinating with staff in other agencies whose programs would benefit parents with disabilities in order to increase referrals, improve program accessibility or other strategies to connect families with existing resources.
- Bolster member awareness of and access to programs and services. This includes both future, expanded supportive parenting services and current services across DHS and its partners. Existing efforts such as Waiver Reimagine will partially address this

recommendation; additional efforts at outreach, communication and training might also be necessary.

- Provide navigation support for accessing and using services. Again, this recommendation applies both to existing and potential new or expanded services. As seen in examples such as MBIA's Resource Facilitation or DHS' pilot of outreach case management for people living with HIV, sometimes a person benefits from support before they access services intended to meet their needs. In the context of this report, support for navigation of services should apply not only to services for a parent with a disability, but also to services needed by that person's entire family unit.

Estimated cost to the state

DHS developed and provided the following fiscal estimates, as required by the legislative mandate. It is important to note that fiscal estimates will need be revised and reassessed according to forecast projections and specific legislative proposals.

Estimated fiscal impact of waiver service expansion

To determine the fiscal impact of the proposed expansion of certain disability waiver services to allow delivery of supportive parenting services and supports, the fiscal analysis made assumptions about the number of disability waiver enrollees who have children under 18 living in their household and the amount of additional services that would be provided with the expanded service eligibility. We estimate once fully implemented, changes to waiver services may have a modest fiscal impact, likely between $1 to $20 million per year.

This fiscal estimate assumes that expanded services are restricted to:

- Assistive technology.
- Family training and counseling.
- Home modifications.
- Individualized home supports with training.
- Respite.
- Specialized equipment and supplies.
- Transportation services.

These are a small portion of overall waiver services provided. The fiscal estimations would increase if additional waiver services were added or if a rate enhancement was added to any services.

The analysis also assumes that about 18 percent of waiver recipients have children under the age 18 living at home, based upon American Community Survey 2021 one-year estimates. However, if the rate in the waiver population is higher or lower, this would alter the fiscal estimate.

In discussions with policy experts, we agreed that only modest use increases would be seen in services such as transportation because transportation activities involving children are covered through school-based transportation services or medical transportation. We also assumed that specialized equipment and supplies, home modification and assistive technology spending would only have a modest increase, as generally the types of equipment or modifications made related to parenting are low cost.

Finally, we anticipated that some services might increase with time, including family training and counseling, as providing coverage for this service would incentivize creation of new training programs for parents with disabilities.

These estimates do not account for changes to enrollment trends in waiver programs based on the availability of supportive parenting services and supports.

Estimated fiscal impact of personal care services for parents with disabilities

Proposed language would create a Medicaid state plan benefit that provides supportive parenting services through personal care assistance type services. Unlike the waiver service expansion language, expansion of PCA services would only include enrollees with a child 12 or younger. Because of the younger age of children, this estimate assumes 12.82% of recipients have children living at home, instead of 18%, based on American Communities Survey 2021 one-year estimates. This estimate makes assumptions about the hours of additional services that would be delivered as a result of the proposal. We estimate once fully implemented, this state plan service will cost an additional $3.4 million to $7.3 million per year.

Several implementation questions remain that will affect the fiscal impact of this proposal. For instance, whether parents would need to work within their current service hour cap or would receive additional hours if they have supportive parenting needs will affect the final cost. This analysis assumes a similar range of possibilities for increased use of services as with the wavier service language; however, if the needs of this population vary significantly, costs could be higher or lower.

This program has not been implemented in other states and research with estimations on the amount of services a typical PCA user will need is not available. Therefore, final costs could be higher or lower than the estimates provided if significant departures in use occur. Further, this fiscal estimate does not account for availability of PCA providers or other changes to the industry.

These estimates do not account for changes to enrollment trends in home care programs based on the availability of supportive parenting.

Other costs

These estimates do not account for systems or administrative costs of this legislative language. Systems work might be needed for the Medicaid Management Information System to potentially develop new service codes, programs of service, rates, service agreements and/or procedure code modifiers. Additionally, the LTSS Assessment process does not collect information about whether people have activities of daily living related to parenting or supportive parenting needs. Updates would be needed to the assessment system and resulting service agreements outputs.

The state share of systems costs for similar types of work has varied from 75,000 to 150,000 in the initial year with about 20 percent of costs ongoing. In addition to systems costs, DHS does not have staff dedicated to policy development and coordination of services for parents with disabilities. Staff time to develop these services would be necessary, as well as staff to oversee evaluation and research into the efficacy and use.

Additional recommendations: detail of potential services

Some of the various research findings suggest potential changes to existing services, while others might require entirely new services—and some others could be implemented via either approach. The central recommendation of this report is for DHS to secure sufficient authority to further investigate the implications of using either or both approaches to meet families' various needs.

Still other priority research findings suggest broader service needs that must be undertaken in partnership within DHS or with other agencies.

Expand or change current services

Some of the research findings point to services that DHS can expand easily and with minimal investments of time and cost. These items are recommended for immediate action:

- Provide parents with disabilities greater support for household management tasks such as cooking, grocery shopping, laundry, housekeeping and related tasks. These services could be authorized in Minnesota with relatively straightforward changes to the Medicaid state plan, waiver authority or other existing home and community services (such as PCA or Home Care Services).
- Provide education and training about child health and development. As evidenced by their prevalence among peer states, these services could be authorized by changes to Minnesota's Medicaid state plan or existing waiver amendments.
- Provide education and training about parenting and caring for a child. These services could also be authorized by changes to Minnesota's Medicaid state plan or existing waiver amendments.
- Ensure parents with disabilities can access the home modifications, assistive technologies or other adaptive equipment that allow them to parent independently when they desire to do so. This recommendation includes but is not necessarily limited to infant and baby care supports such as adaptive cribs or strollers. These supports could be authorized as allowable expenses by changes to Minnesota's Medicaid state plan or existing waiver amendments.

Implement new services

Some of the research findings are better addressed by more robust actions than the updates or expansions to existing services described above. While they might reflect the need for new services or supports, they do not reach beyond DHS's current actual or potential purview.

They include:

- Support emergency and non-emergency respite care for parents with disabilities. While all parents need respite care sometimes, parents with disabilities might need it specifically for emergent situations (such as a flare or crisis related to their own disability), for multi-day periods (such as when their own medical care requires inpatient care) or on an ongoing basis (such as regular respite care during daily periods of fatigue). This service might be a formal, professional service similar to PCA services, a model that financially supports members of a parent’s informal support system to step in as respite caregivers on short notice or a combination of the two.
- Provide education and support for an entire family unit related to parenting with a disability, supporting a parent with a disability or being parented by someone with a disability. This holistic approach is different from the current Medicaid model of training interventions for the eligible member alone. However, especially for parents with acquired disabilities, it could strengthen all family members’ understanding of one another’s experience of disability in family life.
- Provide opportunities for peer connection and support among parents with disabilities. DHS might be able to implement some aspects of this recommendation, such as providing peer mentoring, under the Medicaid state plan or waiver authority. Other aspects, such as coordinating peer groups for social, emotional or practical support, might require a different model of service delivery.
- Ensure that the supports available to a parent with a disability and their family change as their children grow. Provided DHS adopts a lens for assessment and eligibility that accounts for the entire family, this recommendation might be partially addressed by the typical re-assessment process for people who receive waiver or other home and community services. But it might also have implications for when and how a family is eligible for different supports and services. As examples, a parent with an infant wouldn't need services for their child to travel independently and a parent of a pre-teen wouldn't need adaptive infant carrying equipment.
- Minimize children’s adoption of caregiving roles for a parent with a disability—and/or minimize the potential negative effects of a child taking on that role. Note that the demand for services in this area is likely highly mediated by the specific cultural context of each family: where cultural expectations of caring for one’s elders are very strong, demand for these services might be very low. This recommendation could be implemented through a combination of other activities, such as increased household management services and whole-family education and support. It might also require additional services such as peer groups for social and emotional support for the children of parents with disabilities.

Partnership opportunities

Some of the research findings suggest priority needs that fall under the purview of other divisions or agencies and thus might be best served by cultivating interagency partnerships. These partnerships address needs and challenges that might be urgent for parents with disabilities and their families. However, the partnerships might take time to develop which suggests DSD should reach out to potential partners well in advance of committing to a course of action. The needs requiring partnerships beyond DSD include:

- Parents with disabilities' interactions with the child welfare system is the most pressing topic from this research that cannot be directly addressed by DSD through the division's own service delivery. It is discussed in more detail among the cross-cutting themes below. The DHS Child Safety and Permanency Division is a potential partner for this work as well as entities that can provide input on family law matters.
- Affordable and accessible housing that is suitable both for parents with disabilities and their children. The Minnesota Housing Finance Agency or local, county or regional housing authorities are potential partners for this work.
- Strategies to better mitigate the uniquely compounding economic challenges that some parents with disabilities face, especially related to balancing a desire for income and employment with maintaining service eligibility and serving as a caregiver for one's child(ren). The Minnesota Department of Employment and Economic Development or the DHS Economic Assistance and Employment Supports Division are potential partners for this work.
- Providing expanded transportation and mobility support for parents with disabilities and their children—both when accompanying parents and when older children need transportation on their own. The Minnesota Department of Transportation or local, county or regional transportation authorities are potential partners for this work.
- Offering comprehensive, body-positive sex and sexuality education to people with disabilities so they are equipped to make informed choices about becoming a parent in the future. The Minnesota Department of Education is a potential partner for this work.
- Coordinate to expand parents with disabilities' use of existing parent education programs, such as Head Start, Early Head Start, Early Childhood Family Education and home visiting nursing services. Concurrently, work to ensure these programs are fully accessible and adaptable for parents' needs. The Minnesota Department of Education and the Minnesota Department of Health are potential partners for this work.
- Continue to support the development of advocacy and self-advocacy skills for parents with disabilities. The Governor's Council on Developmental Disabilities and ACT Center for Disability Leadership are potential partners for this work.
- In addition to partnerships in service areas outside DSD's purview, many other recommendations—including all of the service design considerations—could be aided in implementation by engagement with others across the state who already implement similar activities.

Additional recommendations: cross-cutting themes

Several additional recommendations are intended to improve family-centered approaches to Medicaid service design and delivery.

Child welfare and child custody

As the Legislature has already noted, attending to the potential for families' involvement in the child welfare system must remain consistent across all potential changes to service delivery for supporting parents with disabilities. The complex and sometimes discriminatory relationship between parental disability and child custody as well as the perceived risk of child welfare involvement might cast a shadow over any supportive parenting services that DHS undertakes. Parents' concerns must be directly addressed alongside service delivery, whether through policy, partnership or practice.

Potential activities include:

- Ensuring that a parent's disability—provided the disability is not demonstrated to result in abuse, neglect or harm to a child—is not the sole determining factor in permanency or custody decisions.
- Ensuring that parents' use of supportive parenting services is not held against them in child welfare or custody cases.
- Ensuring that partner agencies and the people within them (such as judges, social workers, investigators and providers of family preservation services) have the education and resources they need to avoid both intentional and unintentional discrimination against parents with disabilities.
- Ensuring potential service users' awareness of the points above—and that they trust DHS or other messengers when the information is communicated.

Intra- and interagency collaboration

The number of potential partnership activities described in this report illustrate the value of collaborative efforts in addressing some of parents with disabilities' needs or challenges. Indeed, a number of the priority findings in this report cannot be addressed by DHS in isolation. Based on implementation lessons learned from program experts in Minnesota and elsewhere, DHS should work with potential partners to:

- Define goals for the partnership and design activities that will achieve the goals.
- Ensure role clarity and responsibilities for all parties.
- Plan to support other interested parties whose participation is critical to the activities' success.
- Secure budgetary, staff and other administrative commitments as needed.

The recommendations show that DHS has opportunities to work together with other state or county agencies and other organizations.

There are also important opportunities for DHS teams to work together to implement supportive parenting services and supports—for example, staff who manage HCBS waiver programs and the MnCHOICES assessment will need to collaborate closely if DHS opts to expand assessment and eligibility decisions to include a person's entire family unit.

Outreach, communications and coordination

Interviewees made repeated comments about lack of awareness of supports and services or difficulty accessing and navigating services. Those findings suggest a potentially critical threat to the uptake and effectiveness of supportive parenting services. If parents with disabilities do not know the services exist or how to access and navigate the services, they are unlikely to use and benefit from the new services. Moreover, DHS should adjust communication and outreach strategies to address perceptions about "secret" services or navigation strategies.

Strengthening DHS's ongoing commitment to effective outreach, communications and support for member navigation should be a priority as the division expands or adds new services for parents with disabilities and their families. These efforts might include strengthening DHS's own internal, external and intra- or interagency communications about programs and services. They also might include supporting a range of other partners (such as county human services agencies, service providers, case managers and advocates) to equip them with accurate information and the capacity to support people more intensively.

Administrative and operational investments

Expanding services, developing new ones and cultivating and maintaining partnerships all require resource investments over time—particularly in staff time. DHS will require additional time and resources to develop supportive parenting services beyond the most straightforward short-term changes discussed in this report. Based on the scope, variety and complexity of potential services, DHS is requesting funding for one full-time equivalent staff to these efforts. Those costs are reflected in the estimates above.

VII. Implementation language

The following proposed implementation language addresses the key recommendation of this report: that DHS formalize the authority to seek amendments to the Medicaid state plan and existing waivers. DHS developed and provided the recommended language.

Draft language for Medicaid state plan

The commissioner shall seek federal authority of services to provide supportive parenting services to people eligible for personal care assistance (PCA).

(a) Under this benefit, supportive parenting services are limited to assistance with age-appropriate activities of daily living for a child 12 years or younger:

(1) dressing, including assistance with choosing, application and changing of clothing and application of special appliances, wraps or clothing;

(2) grooming, including assistance with basic hair care, oral care, shaving, applying cosmetics and deodorant and care of eyeglasses and hearing aids. Nail care is included, except for recipients who are diabetic or have poor circulation;

(3) bathing, including assistance with basic personal hygiene and skin care;

(4) eating, including assistance with hand washing and application of orthotics required for eating, transfers and feeding;

(5) transfers, including assistance with transferring the recipient from one seating or reclining area to another;

(6) mobility, including assistance with ambulation, including use of a wheelchair. Mobility does not include providing transportation for a recipient;

(7) positioning, including assistance with positioning or turning a recipient for necessary care and comfort; and

(8) toileting, including assistance with helping recipient with bowel or bladder elimination and care including transfers, mobility, positioning, feminine hygiene, use of toileting equipment or supplies, cleansing the perineal area, inspection of the skin and adjusting clothing.

EFFECTIVE DATE.

This section is effective Jan. 1, 2026, or 90 days after federal approval, whichever is later. The commissioner of human services shall notify the revisor of statutes when federal approval is obtained.

Draft language for waivers

The commissioner shall seek an amendment to the 1915(c) home and community-based waivers identified in 256B.49, subdivision 11 and 256B.092, subdivision 5 to allow the services identified in paragraph (a) to deliver supportive parenting services and supports.

(a) To allow supportive parenting services, the commissioner shall amend the following services authorized in the federal waiver plans identified in 256B.49, subdivision 11 and 256B.092, subdivision 5:

(1) Assistive technology

(2) Family training and counseling

(3) Home modifications

(4) Individualized home supports with training

(5) Respite

(6) Specialized equipment and supplies

(7) Transportation

(b) The provision of supportive parenting services and supports will be limited to service functions that are:

(1) Identified in a person's person-centered service plan (or comparable plan of care);

(2) Provided to meet assessed needs of the person related to parenting supports.

EFFECTIVE DATE.
This section is effective Jan. 1, 2026 or 90 days after federal approval, whichever is later. The commissioner of human services shall notify the revisor of statutes when federal approval is obtained.

VIII. Appendices

The following appendices provide additional detail to contextualize or expand on the research findings and recommendations.

Appendix A: Family supports

Table 2: Selected family supports for families with young children

Agency	Program	Needs addressed
Minnesota Department of Education	Early Childhood Family Education (ECFE)	Parent education
Minnesota Department of Education	Early Learning Scholarships	Child care
Minnesota Department of Education	Educate Parents Partnership	Parent education
Minnesota Department of Education	Head Start/Early Head Start Programs	Child care, parent education
Minnesota Department of Education	School Nutrition Programs	Food and nutrition
Minnesota Department of Education	Summer Food Service Program	Food and nutrition
Minnesota Department of Education	Child & Adult Care Food Programs	Food and nutrition
Minnesota Department of Education	Help Me Grow	Parent education
Minnesota Department of Health	Children & Youth with Special Health Needs Follow Up	Health, service navigation and referral
Minnesota Department of Health	Family Home Visiting	Parent education, support
Minnesota Department of Health	Follow Along Program	Parent education
Minnesota Department of Health	Positive Alternatives	Health, parent education, other needs
Minnesota Department of Health	Women, Infants & Children (WIC) Program	Food and nutrition, parent education
Minnesota Department of Human Services	Child Care Assistance Program (CCAP)	Child care

Agency	Program	Needs addressed
Minnesota Department of Human Services	Diversionary Work Program (DWP)	Employment
Minnesota Department of Human Services	Minnesota Family Investment Program (MFIP)	Economic support
Minnesota Department of Human Services	Parent Support Outreach Program - Child Welfare	Service navigation and referral
Minnesota Department of Human Services	Providing Information to Parents/Child Care Development Grants	Child care, parent education
Minnesota Department of Human Services	Supplemental Nutrition Assistance Program (SNAP)	Food and nutrition
Minnesota Department of Human Services	Early Childhood Mental Health Systems	Health
Minnesota Department of Human Services	Licensed Child Care Centers	Child care
Minnesota Department of Human Services	Licensed Family Child Care (FCC)	Child care
Minnesota Department of Commerce	Energy Assistance	Housing, economic support
Minnesota Department of Revenue	Working Family Tax Credit	Economic support
Minnesota Housing Finance Agency	Bridges Assistance Program	Housing
Minnesota Housing Finance Agency	Housing Trust Fund Rental Assistance Program	Housing
Minnesota Office of Higher Education	Postsecondary Child Care Assistance Grant Program	Child care

Excerpted and adapted from Minnesota Services and Supports for Families with Young Children.[18]

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[18] Minnesota Children's Cabinet. Minnesota Services and Supports for Families with Young Children, 4-5.

Appendix B: Resources related to parenting with a disability

The research team compiled the following resources as part of the literature scan for this study. They suggest the breadth of information available both to parents with disabilities and those who are part of their support systems.

The Arc. Parents with Intellectual Disabilities. (2011): https://thearc.org/wp-content/uploads/forchapters/Parents%20with%20I_DD.pdf

Centre for Independent Living in Toronto. Nurturing Assistance Service: https://www.cilt.ca/programs-and-services/parenting-with-a-disability-network/nurturing-assistance/

Centre for Independent Living in Toronto. Parenting with a Disability Network: https://www.cilt.ca/programs-and-services/parenting-with-a-disability-network/

Developmental Disabilities Council of Oklahoma. Sooner Success: Supporting Parents with Disabilities: https://soonersuccess.ouhsc.edu/Services-Programs/Supporting-Parents-with-Disabilities

Developmental Disabilities Council of Oklahoma. Sooner Success Adaptive Baby Care Equipment Flyer: https://soonersuccess.ouhsc.edu/Portals/1024/assets/ABC%20equipment%20flyer.pdf

Developmental Disabilities Council of Oklahoma. Sooner Success Electronic Resource Binder: https://soonersuccess.ouhsc.edu/Portals/1024/2020-05-18%20Electronic%20Resource%20Binder.pdf

Developmental Disabilities Council of Oklahoma. Supporting Parents with Disabilities: A Desk Reference for Child Welfare Professionals (2019): http://www.okdhs.org/OKDHS%20Publication%20Library/19-09.pdf

Developmental Disabilities Council of Oklahoma. Quick Reference Bench Card: Access to Justice Checklist for Parents with Known or Suspected Disabilities. https://soonersuccess.ouhsc.edu/Portals/1024/Bench%20card%20%28002%29.pdf

Disability Hub MN. Parent and family supports: Overview: https://www.disabilityhubmn.org/for-families/parent-and-family-supports/

Goody, A. Parenting After Brain Injury: https://www.headway.org.uk/media/3998/parenting-after-brain-injury-e-booklet.pdf

Heller School for Social Policy and Management, Brandeis University. Disabled Parenting Project: https://www.disabledparenting.com/

Heller School for Social Policy and Management, Brandeis University. National Research Center for Parents with Disabilities: https://heller.brandeis.edu/parents-with-disabilities/

Idaho Assistive Technology Project: https://idahoat.org/

Idaho Assistive Technology Project. Assistive Technology for Parents with Disabilities: A handbook for parents, families and caregivers. (2003): http://idahoat.org/Portals/60/Documents/Services/Resources/AT_ParentsHandbook.pdf

Minnesota Department of Administration (partnership with DEED, DHS and Education). Minnesota Guide to Assistive Technology: https://mn.gov/admin/at/

Through the Looking Glass: https://lookingglass.org/

Through the Looking Glass. List of Adaptive Baby Care Products on the Market. (2016): https://lookingglass.org/wp-content/uploads/Baby-care-products-chart-TLG-9-2016-1.pdf

U.S. Department of Health and Human Services. Child Welfare Information Gateway: Services for Parents with Disabilities: https://www.childwelfare.gov/topics/systemwide/service-array/services-disabilities/youth/disabilities/

Appendix C: Potential opportunities based on non-priority findings

The additional findings described in this report, while noted less frequently or urgently than the priority findings, suggest additional needs and challenges that DSD could address in the future. These supplemental recommendations include:

- A shift to adopt an overall **service orientation** that supports people with disabilities' ability to parent with as much independence or support as they desire.
- Expand the scope of existing **positive behavior supports** in the state's community-based services programs to include behaviors consistent with independent parenting. This expansion might include not only a change to policy language, but efforts to equip providers in delivering parenting-related positive supports.
- In addition to education and training related to parenting and child development, several other types of education for people with disabilities emerged as additional findings:
    - **Education and training about family planning and pregnancy** to help inform future parents with disabilities.
    - **Education on healthy relationships** to help parents develop co-parenting and other social relationships that benefit all families.
    - **Education on boundaries and social cues** to help parents with disabilities recognize appropriate or inappropriate behaviors in themselves, their child(ren) and others.
    - **Education for entire** families about living in a family with a parent with a disability.
    - The importance of **tailoring education** and training services to individual needs.
- Though it did not emerge from interviews, the research literature noted a desire for families to participate in **leisure and recreation activities together**. This might require special services, parental effort or environmental supports.

Several of the additional findings also suggested partnership opportunities across either DHS or the wider state enterprise. Although they did not emerge as top priorities through the research process, they remain areas in which the lives of parents with disabilities and their families could be better supported. They include:

- Expanding the **behavioral health services** offered to parents with disabilities and their families or improving connection to those services for parents with disabilities and their families. The DHS Behavioral Health Division is a potential partner for this work.
- Increasing outreach and referral work to ensure parents with disabilities and their families have support for their **food and nutrition** needs, especially given the economic challenges discussed elsewhere in this report. The DHS Economic Assistance and Employment Supports Division is a potential partner for this work.
- Increasing outreach and referral work to ensure parents with disabilities and their families have **affordable child care** and collaborate to ensure it is responsive to families' unique needs. The DHS Child Care Services Division is a potential partner for this work.

- Promoting the value that people with disabilities have competent, respectful and adaptive **health care** before, during and after becoming a parent. HCBS and MHCP providers might be potential partners for this work.
- Considering how to encourage and value **parents' informal support systems** for practical, emotional and social support around parenting with a disability. By definition, this might never be a formal service or support provided by DSD, but informal networks and relationships can provide substantial benefit to parents with disabilities. Existing supports such as the Charting the LifeCourse framework can help to identify and document parents' informal support systems.[19]
- Increasing outreach and improving internal and external communications to improve understanding about how **parents with disabilities can request accommodations** from various agencies and service providers (e.g., in enrolling for services, when doing parenting tasks or using parenting-focused services). There are many organizations that support or interact with parents who are potential partners in this work, from school districts to family courts.

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[19] To learn more about Charting the LifeCourse, see https://disabilityhubmn.org/for-families/charting-the-lifecourse-for-families/.

Appendix D: References

Laws of Minnesota 2021, 1st Spec. Sess. chapter 7, article 13, section 69.

"About [Family Development and Self-Sufficiency] FaDSS," Iowa Department of Human Rights, https://humanrights.iowa.gov/dcaa/fadss/about-fadss.

"ARP Section 9817 State Spending Plans and Narratives and CMS Approval Letters," Center for Medicaid Services, https://www.medicaid.gov/medicaid/home-community-based-services/guidance/arp-section-9817-state-spending-plans-and-narratives-and-cms-approval-letters/index.html.

"Ascend at the Aspen Institute," Aspen Institute, https://ascend.aspeninstitute.org/.

Carter, Nancy and Denise Bryant-Lukosius, Alba DiCenso, Jennifer Blythe and Alan Neville, "The Use of Triangulation in Qualitative Research," Oncology Nursing Forum 41, no. 5 (2014): 545-547, http://dx.doi.org/10.1188/14.ONF.545-547.

"Case Management Redesign," Minnesota Department of Human Services, https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/minnesota-health-care-programs/case-management-redesign/.

"Child Welfare Information Gateway: Financial Self-Sufficiency to Support Family Well-Being," U.S. Department of Health and Human Services, https://www.childwelfare.gov/topics/preventing/promoting/parenting/self-sufficiency/.

"Child Welfare Information Gateway: Philosophy and Key Elements of Family-Centered Practice," U.S. Department of Health and Human Services, https://www.childwelfare.gov/topics/famcentered/philosophy/.

Commission on Accreditation of Rehabilitation Facilities. 2022 Medical Rehabilitation Standards Manual. Tucson, Ariz.: CARF International, 2022.

"Community-Based Services Manual (CBSM): Waiver and Alternative Care Programs Overview," Minnesota Department of Human Services, https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_000852.

"Disability Hub MN," Disability Hub MN, https://disabilityhubmn.org/.

"Family Support Grant," Minnesota Department of Human Services, updated June 13, 2019, https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/fsg.jsp.

Gardiner, Finn, “Adaptive parenting strategies used by mothers with physical disabilities caring for infants and toddlers,” National Research Center for Parents with Disabilities, https://heller.brandeis.edu/parents-with-disabilities/support/parenting-tips-strategies/adaptive-strategies-mothers-physical.html. Adapted from an article of the same title by Robyn Powell, Monika Mitra, Suzanne Smeltzer, Linda Long-Bellil, Lauren Smith, Eliana Rosenthal and Lisa Iezzoni, Health and Social Care in the Community 27, no. 4 (2018): 889-898, https://doi.org/10.1111/hsc.12706.

“Help Me Connect,” Help Me Connect, https://helpmeconnect.web.health.state.mn.us/HelpMeConnect/.

“Help Me Grow MN,” Help Me Grow MN, https://helpmegrowmn.org/HMG/index.htm.

“Home Care Services,” Minnesota Department of Human Services, updated March 21, 2016, https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/home-care.jsp.

Idaho Assistive Technology Project. Assistive Technology for Parents with Disabilities: A Handbook for Parents, Families and Caregivers. Moscow, Idaho: Idaho Assistive Technology Project, 2003. Available at http://idahoat.org/Portals/60/Documents/Services/Resources/AT_ParentsHandbook.pdf.

Institute on Community Integration. Person and Family-Centered Approaches in Mental Health and Co-Occurring Disorders Training Project: Final Report. Minneapolis, Minn.: University of Minnesota, 2019. Available at https://ici-s.umn.edu/files/YncRnRHycq/person-and-family-centered-approaches-in-mental-health-and-co-occurring-disorders-training-project.

“Introducing the Integrated Services Assessment Tool (ISAT),” Future Services Institute, http://futureservicesinstitute.org/assessment-tool.

Lightfoot, Elizabeth and Traci LaLiberte, “Parental Supports for Parents with Intellectual and Developmental Disabilities,” Intellectual and Developmental Disabilities 49, no. 5 (2011): 388-391, http://dx.doi.org/10.1352/1934-9556-49.5.388.

Lightfoot, Elizabeth, Traci LaLiberte and Minhae Cho, “Parental Supports for Parents with Disabilities: The Importance of Informal Supports,” Child Welfare 96, no. 4 (2018): 89-110, https://www.jstor.org/stable/48625524.

“Local Community Resource Hubs,” Minnesota Department of Education, https://education.mn.gov/MDE/dse/early/preschgr/local/.

McConnell, David and Gwynnyth Llewellyn, “Stereotypes, Parents with Intellectual Disability and Child Protection,” Journal of Social Welfare and Family Law 24, no. 3 (2002): 297–317, http://dx.doi.org/10.1080/09649060210161294.

McKeever, Patricia, Jan Angus, Karen Lee-Miller and Denise Reid, "'It's More of a Production': Accomplishing Mothering Using a Mobility Device," Disability & Society 18, no. 2 (2003): 185–192, http://dx.doi.org/10.1080/0968759032000052824.

"Medicaid Basics," Minnesota Department of Human Services, updated May 13, 2019, https://mn.gov/dhs/medicaid-matters/medicaid-minnesotacare-basics/medicaid-basics/.

Mercerat, Coralie and Thomas Saias, "Parents with Physical Disabilities and Perinatal Services: Defining Parents' Needs and their Access to Services," Disability & Society 36, no. 8, (2021): 1261–1284, https://doi.org/10.1080/09687599.2020.1788513.

"Minnesota 2-Generation Policy Network," Minnesota Department of Human Services, https://mn.gov/dhs/2-generation/.

Minnesota Children's Cabinet. Minnesota Services and Supports for Families with Young Children. Minnesota Children's Cabinet, January 2018. Available at https://mn.gov/mmb-stat/2-gen/2017-children-and-families-program-inventory.pdf.

Minnesota Department of Human Services. Case Management Redesign Background Document. Saint Paul, Minn.: Minnesota Department of Human Services, February 2017 Available at https://edocs.dhs.state.mn.us/lfserver/Public/DHS-3810-ENG. "Community-Based Services Manual (CBSM): Waiver, AC and ECS Case Management," Minnesota Department of Human Services, https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_000821#.

National Council on Disability. "Benefit Planning, Work Incentive Counseling," in Report on Subminimum Wage and Supported Employment. Washington, DC: 13. National Council on Disability, 2012. Available at https://ncd.gov/sites/default/files/NCD_Sub%20Wage_508.pdf

National Council on Disability. "Supporting Parents with Disabilities and Their Families in the Community," in Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children. Washington, DC: National Council on Disability, 2012: 193-216. Available at https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf.

National Research Center for Parents with Disabilities, "Map of Current State Legislation Supporting Parents with Disabilities," https://heller.brandeis.edu/parents-with-disabilities/map/index.html.

"National Resource Center for Family Centered Practice," University of Iowa, https://nrcfcp.uiowa.edu/what-is-family-centered-practice.

Olmstead Prevention of Abuse and Neglect Specialty Committee. Comprehensive Plan for Prevention of Abuse and Neglect of People with Disabilities: Report. Minnesota Olmstead Subcabinet, January 2018. Available at https://mn.gov/olmstead/assets/2018-01-22%20Comprehensive%20Plan%20for%20Prevention%20of%20Abuse%20and%20Neglect%20of%20People%20with%20Disabilities%20Report%20-%20Final%202-23-18_tcm1143-468155.pdf.

"Parent to Parent USA," Parent to Parent USA, updated August 4, 2022, https://www.p2pusa.org/.

"Parents with Intellectual Disabilities," University of Hertfordshire Understanding Intellectual Disability and Health, http://www.intellectualdisability.info/family/articles/parents-with-intellectual-disabilities.

"Partners in Policymaking," Minnesota Department of Administration Governor's Council on Developmental Disabilities, https://mn.gov/mnddc/pipm/.

"PCA Services," Minnesota Department of Human Services, updated March 21, 2016, https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/pca/services.jsp.

"Person- and Family-centered Care and Peer Support," Substance Abuse and Mental Health Services Administration, https://www.samhsa.gov/section-223/care-coordination/person-family-centered.

"Provider Manual: Health Care Programs and Services," Minnesota Department of Human Services, updated March 4, 2022, https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=ID_008922.

Ranji, Usha and Alina, Salganicoff, Alexandra Stewart, Marisa Cox and Lauren Doamekpor, State Medicaid Coverage of Family Planning Services: Summary of State Findings. San Francisco, Calif.: Kaiser Family Foundation, 2009. Available at https://www.kff.org/wp-content/uploads/2013/01/8015.pdf.

"Resources: 2Gen Toolbox," Aspen Institute, https://ascend-resources.aspeninstitute.org/resources/.

"Self-Advocates Minnesota (SAM)," ACT Center for Disability Leadership on Intellectual and Developmental Disabilities, https://www.selfadvocacy.org/act-programs/self-advocates-minnesota-sam/.

Shade, Dave, "Empowerment for the Pursuit of Happiness: Parents with Disabilities and the Americans with Disabilities Act," Minnesota Journal of Law & Inequality 16, no. 1 (1998): 197–217, https://scholarship.law.umn.edu/lawineq/vol16/iss1/3.

Shpigelman, Carmit-Noa, "How to Support the Needs of Mothers with Physical Disabilities?," Disability Rehabilitation 37, no. 11 (2015), 928-935. http://dx.doi.org/10.3109/09638288.2014.948133.

"State Waivers List," Center for Medicaid Services, https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html.

Through the Looking Glass. List of Adaptive Baby Care Products on the Market. Berkeley, Calif.: Through the Looking Glass, 2016. Available at https://lookingglass.org/wp-content/uploads/Baby-care-products-chart-TLG-9-2016-1.pdf.

“Washington State Fathers Network,” Washington State Fathers Network, updated August 1, 2022, https://fathersnetwork.org/.