

Pediatric Care Coordination
COMMUNITY OF PRACTICE

Uncharted Waters:

Brainstorming to Stay Afloat During the COVID-19 Pandemic

Tuesday, April 21, 2020
Noon – 1:00pm CT

Presented by: Lisa Gemlo, MPH, RD, LD
Children & Youth with Special Health Needs, Minnesota Department of Health

1

Housekeeping

- This event will be recorded
- Please keep yourself on mute (by phone or on the Zoom platform)
- All questions and resources should be submitted through the Q & A feature – Information will be saved and shared with participants
- PPT to be posted and available for download
- There will be a post session evaluation
- Certificate of Attendance available

2

Agenda

12 N	Welcome
	Housekeeping
12:10	Presentation
12:40	Small Group Discussion
12:50	Wrap Up

3

Minnesota Pediatric Care Coordination Community of Practice



Voluntary involvement

Increase knowledge, skills, and connections to aid in improving access to effective care coordination for CYSHN and their families.

4

Where is Care Coordination?



- Family
- Primary Care Clinics
- Specialty Care
- Schools
- Social Services
- Waivers
- Public Health
- Behavioral Health
- Hospitals
- Non-profits



5

<https://survey.vovici.com/se/56206EE3356B446C>

**Care Coordination for the Pediatric Population
Community of Practice**

I am interested in registering for the Community of Practice: Care Coordination for the Pediatric Population which includes opportunities to network, share resources and expertise that promote effective care coordination plus professional and personal development.

By completing and submitting this information, I give permission for the sharing of my name and contact information with other people performing care coordination in Minnesota.

Registrant Information:

Name *

Organization/Clinic *


Title

Email *

Phone number *

Identify any specifics of pediatric population serving

County where services are primarily located



No, I do not want my information shared but wish to receive emails pertinent to care coordination for the pediatric population

6

Objectives

- Share the collective summary of the challenges and impact of COVID-19 on CYSHN and the organizations serving families of CYSHN.
- Identify potential community resources to meet those needs
- Crowdsourcing further information that may be helpful to attendees
- Connect attendees to each other to share relevant information/experiences

7

PLEASE SHARE YOUR RESOURCES AND QUESTIONS THROUGH THE Q & A FEATURE

8

Immediate Needs

What common concerns and unmet needs related to COVID-19 are you hearing about from families with children and youth with special health needs?



13

13

IMMEDIATE NEEDS

Families Need Accessible Content and Technology Support



Content in American Sign Language (ASL), Closed-Captions, and Tactile Signing



Materials appropriate for children with disabilities



Content for families without technology



Technology Support

14

14

IMMEDIATE NEEDS

Families Need Child Care Outside of the Home



Child care for CYSHN, especially children that are 12+ years old (essential workers)

15

15

IMMEDIATE NEEDS

Families Need More Information About COVID-19



- Information about prevention/mitigation
- Information about their child's disease/diagnosis and COVID-19

16

16

IMMEDIATE NEEDS

Families Need Help From Direct Support Professionals



Fear of letting a caregiver into the home (may expose family to COVID-19)



Having a back-up plan if someone gets sick (crisis care)




More personal care assistance, nursing, home care, and respite staff (not enough qualified staff, some aren't showing up)

17 


17

IMMEDIATE NEEDS


Families Need Educational Support




Help with distance learning, especially for working parents and children who had paraprofessionals in school



Continuation of special education services and plans (i.e. IEPs)




Daily structure/Routine

18 


18

IMMEDIATE NEEDS

Families Are Concerned About Their Finances




Funding/money so there are still caregivers after the pandemic (less work, hours)




Financial support for working parents who are taking time off to care for children




Overtime for paid parents on waivers that are working additional hours



Job loss, lay-offs, and under-employment




Paying rent

19 


19

IMMEDIATE NEEDS


Families Need Services for Their Child's Health and Development




Continuation of in-home therapy for developmental services



Physical, occupational, and speech-language therapy




Many canceled appointments, but safe clinic visits are still needed

20 

20

IMMEDIATE NEEDS


Families Are Concerned About Their Child's Mental and Emotional Well-being



Need to address mental, emotional, and behavioral health needs



Continuity of therapy (i.e. Applied Behavior Analysis therapy)



Manage aggressive and irritable behaviors

21 

21

IMMEDIATE NEEDS

Families Need Help Accessing Essentials



Food, baby formula, and feeding tube supplies



PPE and cleaning supplies (disinfecting wipes, hand sanitizer, gloves, etc.)



Diapers and baby wipes



Transportation (especially for people using wheelchairs)




Medical supplies and medications (pharmacy delivery)

22 


22

IMMEDIATE NEEDS


Parents Are Feeling Overworked




Parents have no help with child's education, therapy, day-to-day care, housekeeping, etc.



Parents are working around the clock




Parents need breaks

23 


23

IMMEDIATE NEEDS


Families Need Rules to Change




DHS to make emergency exceptions to programs



Allow telehealth for day treatment and other mental health providers (billing for MA and PMAPs for youth)




Eliminate fingerprinting requirement for home care staff (* this requirement has now been waived)

24 

24

IMMEDIATE NEEDS

Families Rely on State and County Services




- Need expanded CDCS funds
- Families with CDCS as well as those with traditional waivers are without caregivers

25 


25

IMMEDIATE NEEDS

Families Are Concerned About Stigma




Children are stigmatized for being “sick,” when symptoms are caused by their disease or condition


26 

26

Long-Term Needs




What common concerns and unmet needs related to COVID-19 are you hearing about from families with children and youth with special health needs?

27 


27

LONG-TERM NEEDS

Families Need Child Care Outside of the Home



Programs that can support children with unique health needs

28 

28

LONG - TERM NEEDS

Families Are Concerned Their Child Will Be Discriminated Against Because of Their Disability Status





Concern that limited health care may adversely impact those with existing disabilities

29 

29

LONG - TERM NEEDS


Families Need Educational Support



Plans for making-up educational services that were not provided through distance learning

Help working on IEP goals and objectives at home




More assistance with distance learning

30 

30

LONG - TERM NEEDS

Families Are Concerned About Their Finances



Budget support (budget for emergency preparedness)

Employment

Stable and affordable housing

31 

31

LONG - TERM NEEDS

Families Need Ongoing Health Care for their Children



Access to safe health care (scheduled or emergency visits)

Medical supplies and medication refills


Telehealth

32 


32

LONG - TERM NEEDS

Families Have Mental and Emotional Health Needs



- Support for mental, behavioral, and emotional health
- Parent's mental health (ex. Parent support groups)

33 

33

LONG - TERM NEEDS

Families Need Help Accessing Essentials




Food, formula, and feeding tube supplies PPE and cleaning supplies (disinfecting wipes, hand sanitizer, gloves, etc.) Transportation

34 


34

LONG - TERM NEEDS

Families Rely on State and County Services




- Continuity of services
- More support with CDCS & other waivers


35 

35

Organizational Needs

What would help your organization better meet these needs and concerns (for example, a forum where I can learn what other organizations are doing, a weekly e-blast with relevant and up-to-date resources and information, policy changes)? Please be specific.



36 

36

ORGANIZATIONAL NEEDS

More Communication is Needed to Stay Up-to-Date on Information and Better Support Families

The diagram features a central dark blue circle labeled 'Preferences'. Four lines radiate from this circle to four separate icons, each with a label: 'Forum' (top, speech bubble icon), 'E-blast' (right, envelope icon), 'Phone Number' (bottom-right, telephone handset icon), and 'Website' (bottom, computer monitor icon).

37

37

Organizations Want Opportunities to Collaborate

- Learn what others are doing
- Learn how providers are responding to/working with families
- Work towards a set of common goals, objectives, and outcomes
- Take the burden off of families

38

38

ORGANIZATIONAL NEEDS

Rule Changes to Compensation and Licensing Would Help Providers and Families

- Improve pay for staff (i.e. direct support professionals)
- Allow providers to work in different settings
- Allow telehealth for all services
- Have COVID-19 testing available to direct service providers
- Require management to supply PPE to keep staff safe

39

39

ORGANIZATIONAL NEEDS

Organizations Could Better Help Families If They Had Resources and Information About...

- Virtual social opportunities (for parents and children)
- Learning tools and ideas for children with IEP's (i.e. guidance from MDE)
- Rule changes (i.e. DHS) and advocacy opportunities
- Financial support and employment opportunities (for families and organizations)
- Programs (i.e. local/regional) and resources (i.e. disease-specific)

40

40

ORGANIZATIONAL NEEDS

Guidance on In-Home Support Would Help Families

- Crisis care planning tools and resources
- List of available direct support professionals (i.e. personal care assistance, nursing, and support staff)
- Guidelines for using direct support professionals (i.e. PPE, other safety precautions when people come into the home)
- Options for in-home therapies
- Somewhere to document/report when direct support professionals do not show-up for their shift

41 

41

ORGANIZATIONAL NEEDS

Rule Changes to Waivers and CDCS Funds Would Help Families

- Allow a parent to be paid for more than 40 hours (i.e. CAC, CSG)
- Increase waiver funds, especially for children who need one on one support at school
- Allow two parents to be paid when staff are unavailable
- Allow siblings to work more hours as allowed during the summer
- Increase parent compensation rate to 1.5
- More waivers for deafblind students

42 

42

ORGANIZATIONAL NEEDS

Rule Changes to Essential Child Care and Education Services Would Help Families

- Allow centers caring for children with very low function or high risk special needs to stay open
- Require schools to provide child care for children with special health needs over the age of 12 years
- Require schools to provide in-person special education services

43 

43

Families and Organizations Are Asking For...

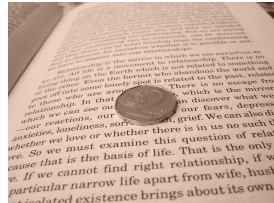
- Internet access
- Future analysis of medical supply availability
- Mid-year waiver budget analysis
- More content in ASL
- PPE
- Public messaging about people with disabilities and special health needs

44 

44

Resources or Information

What resources or information have you found helpful that could benefit families of children and youth with special health needs and/or other organizations?



45 

45

What do you have to say?

- While I share what we received in the survey and highlight a few resources, please continue to share any resources you've found in the chat.



46 

46

Personal and Community Resources

- Advice and best practice sheets specific to CYSHN and COVID-19
- Apps (i.e. Choiceworks)
- Blogs and Videos from Disability Community
 - [Jessica Kellgren-Fozard](#)
 - [Rikki Poynter](#)
 - [Molly Burke](#)
- Children's Activities
- Choiceboards
- Community and Medical Care Manager Collaboration
- Connection with physicians from Children's Hospital (familiar with CYSHN and extended hour nursing)
- Facebook Groups
- Food Supports
- Google Suite
- Hygiene materials to protect against COVID-19
- Online School
- Parents
- Social Worker
- School Supports
- Telemedicine
- Virtual Happy Hours
- Zoom

47 

47

Organizational Resources

- [The ARC](#)
- [Autism Society of Minnesota\(COVID page\)](#)
- Call [211](#) for help
- Center for Exceptional Children
- [Center for Inclusive Child Care](#)
- Centers for Independent Living
- [Children's Provider Network](#)
- Coalition for Children with Disabilities
- [Conquering CHD \(weekly updates\)](#)
- Family Support Organizations ([Family](#))
- [Voices of MN; MN Hands and Voices](#)
- [Federation for Students with Special Needs](#)
- [Help Me Grow](#)
- [Parent to Parent USA](#)
- [PACER Center](#)
- [Support for Families of Children with Disabilities](#)
- National Organizations

48 

48

Government Resources

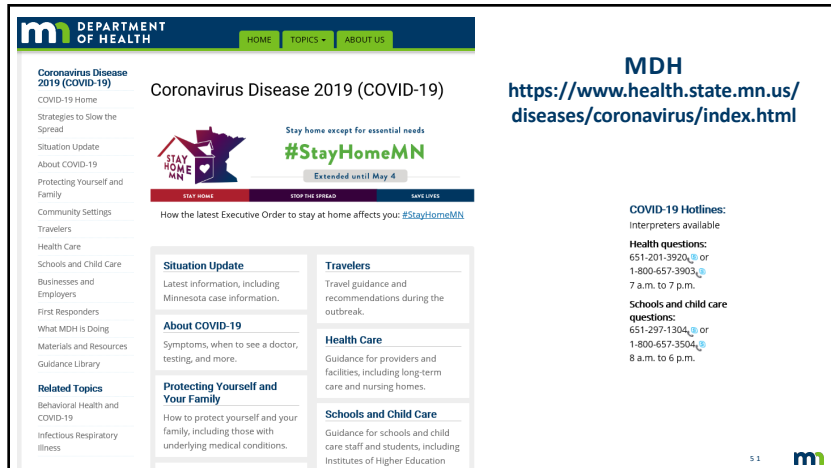
- Child Care Grant
- Minnesota County Websites (i.e. public health nurses)
- [Minnesota Consumer-Directed Community Supports](#) (CDCS)
- [Minnesota Department of Education](#) (MDE)
- [Minnesota Department of Health](#) (MDH)
- [Minnesota Department of Human Services](#) (DHS)
- Free Appropriate Public Education (FAPE)
- [Governor Walz](#)
- Minnesota Legislative Summaries and [Executive Orders](#)
- [Minnesota Council on Disability](#)
- [TEFRA](#)

49

COVID-19 Specific Resource Examples

- MDH
- Disability Hub
- Resources from Camden Coalition and National Center for Complex Health and Social Needs Forum April 3, 2020

50



MDH
<https://www.health.state.mn.us/diseases/coronavirus/index.html>

COVID-19 Hotlines:
 Interpreters available
Health questions: 651-297-1304 or 1-800-657-3903, 7 a.m. to 7 p.m.
Schools and child care questions: 651-297-1304 or 1-800-657-3504, 8 a.m. to 6 p.m.

51



Materials and Resources for Coronavirus Disease 2019 (COVID-19) Response

On this page:
[Videos](#)
[Fact Sheets](#)
[Posters](#)
[Social Media Toolkit](#)
[Other Materials](#)

Videos

- [Videos for Coronavirus Disease 2019 \(COVID-19\) Response](#)
- [American Sign Language \(ASL\) Videos](#)

Fact Sheets

- [Coronavirus Disease 2019 \(COVID-19\) Key Messages](#)
 Basic overview of COVID-19 in multiple languages.

52


Crisis Standards of Care

<https://www.health.state.mn.us/communities/ep/surge/crisis/index.html>


- Framework created for MN to outline MDH response and provide guidance to health care and public health organizations during a pervasive public health event
- Included here is guidance on patient care strategies for scarce resource situations, including pediatrics and ventilators <https://www.health.state.mn.us/communities/ep/surge/crisis/standards.pdf>

MECHANICAL VENTILATION
STRATEGIES FOR SCARCE RESOURCE SITUATIONS

MINNESOTA HEALTH CARE
PREPAREDNESS PROGRAM

53 

53



Disability Hub MN

Coronavirus resources

As the coronavirus situation continues to evolve, you might have questions about COVID-19 or how it affects people with disabilities. Here's a collection of helpful resources.


- National and state resources
- Disability-specific information
- Mental and chemical health
- Shopping and transportation
- Internet and telephone
- Food and nutrition resources
- Childcare
- Stimulus payment, unemployment, student loans and taxes
- Infographics
- Videos

Chat with a Hub expert
Mon Wed Fri: 8:30 a.m. to 5 p.m.
Tues Thurs: 9 a.m. to 5 p.m.

Call the Hub
Mon Wed Fri: 8:30 a.m. to 5 p.m.
Tues Thurs: 9 a.m. to 5 p.m.

Email the Hub
Emails answered Monday to Friday


[Email the Hub](#)

4 


54

National Center For Complex Health and Social Needs

- Crowdsourced a three paged list on April 3 <https://www.nationalcomplex.care/wp-content/uploads/2020/04/Community-Forum-1-resources.pdf>

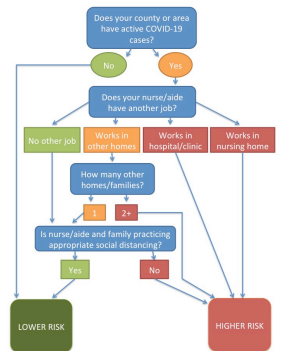


The National Center
for Complex Health & Social Needs
An initiative of the Camden Coalition

55 

55


Example from ComplexChild.org



```

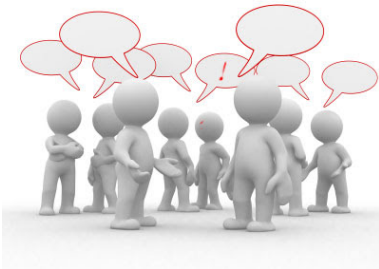
graph TD
    Q1{Does your country or area have active COVID-19 cases?}
    Q2{Does your nurse/aide have another job?}
    Q3{How many other homes/families?}
    Q4{Is nurse/aide and family practicing appropriate social distancing?}
    R1[LOWER RISK]
    R2[HIGHER RISK]

    Q1 -- No --> R1
    Q1 -- Yes --> Q2
    Q2 -- No other job --> Q3
    Q2 -- Works in other business --> R2
    Q2 -- Works in hospital/clinic --> R2
    Q2 -- Works in nursing home --> R2
    Q3 -- 1 --> R1
    Q3 -- 2+ --> Q4
    Q4 -- Yes --> R1
    Q4 -- No --> R2
  
```

56 

56

Time to Talk to Each Other



57 

57

Please consider

1) What are your biggest challenges



2) What has helped you/your families the most?

58 

58

Reflections

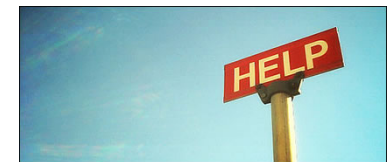


59 

59

Because You Asked

- Newsletter e-bite
- On-line Forums
- Disability Hub and MDH websites for Resources
- Resources and slides will be sent within next few days



60 

60

Please continue to share with us

Your stories
Your concerns
Your brilliance
Your creativity

Lisa.Gemlo@state.mn.us



61

We want your feedback
Please complete the session evaluation

THANK YOU!

62