


**Goals for Children:  
Helping Families and Children  
Create Goals**

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May 7, 2021



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**COIIN TO ADVANCE CARE FOR CMC**  
Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity

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**CMC CoIIN in Wisconsin** 

- Title V Representative
- American Family Children's Hospital Complex Care Program
- Children's Wisconsin Complex Care Program
- Children and Youth with Special Health Care Needs (CYSHCN) Regional Centers, Medical Home
- Family Voices of Wisconsin
- Children's Long-Term Support (CLTS) Program
- Parents of children with medical complexity

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### CMC CoIIN in Wisconsin

- Every child with medical complexity has a Shared Plan of Care (SPoC).
- Every child is connected to resources to meet unmet needs – CYSHCN Regional Centers.
- Every eligible child is on the CLTS Waiver.
- Families identified that improving goal setting and facilitating unified goals across entities is an important need.

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### How can we help families?

- CoIIN brainwriting exercise - How can we make sure the SPoC goals are meaningful to families?
- Diabetes Center Copenhagen, Denmark
- Our initial set of goal cards had 60 cards
- About 45 families reviewed the goal cards
  - Keep it
  - Change it
  - Get rid of it



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### Top Six Cards

- Receive good dental care
- Get better sleep
- Have an accessible home
- Play more
- Support for my brothers and sisters
- Have transportation I can use with my family

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Play more

Photos

Play more

Images

Play more

Line Drawings

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Play more

Community, Social, and School

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39 Cards; 5 Categories

Learn how to tell others what I need

Get support for my brother(s) and sister(s)

Make new friends

Have a hobby

Receive good dental care

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### Communication

<b>Have others listen and understand me</b> 	<b>Improve my ability to communicate</b> 
<b>Learn how to tell others what I need</b> 	<b>Understand and express my feelings</b> 

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### Community, Social, and School

<b>Be part of my school</b> 	<b>Be safe in my environment</b> 
<b>Experience my community</b> 	<b>Feel like I belong in my community</b> 

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### Community, Social, and School cont.

<b>Get help at school with _____</b> 	<b>Go to camp without my parents</b> 	
<b>Make new friends</b> 	<b>Play more</b> 	<b>Reduce behaviors that hurt others</b> 

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### Home and Family

<b>Find a care provider to help at home</b> 	<b>Get support for my brother(s) and sister(s)</b> 
<b>Have an accessible home</b> 	<b>Have my parent(s) spend more time by themselves</b> 

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### Home and Family cont.

<b>Have someone help find and coordinate community services</b> 	<b>Have transportation I can use with my family</b> 	
<b>Help get myself dressed</b> 	<b>Improve my hygiene</b> 	<b>Take vacations</b> 

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### Independence

<b>Accept my differences</b> 	<b>Be more independent</b> 	<b>Be treated with respect</b> 
<b>Have a hobby</b> 	<b>Make my own decisions</b> 	<b>Use technology</b> 

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### Medical and Health

<p style="text-align: center; font-weight: bold;">Access more therapy opportunities</p>	<p style="text-align: center; font-weight: bold;">Describe pain and other physical symptoms</p>	<p style="text-align: center; font-weight: bold;">Get better sleep</p>
<p style="text-align: center; font-weight: bold;">Have equipment that is made for me</p>	<p style="text-align: center; font-weight: bold;">Have fewer medical appointments</p>	<p style="text-align: center; font-weight: bold;">Learn about my medications</p>

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### Medical and Health cont.

<p style="text-align: center; font-weight: bold;">Learn healthy choices</p>	<p style="text-align: center; font-weight: bold;">Learn how to use my equipment / supplies</p>	
<p style="text-align: center; font-weight: bold;">Make the switch to the adult health care system</p>	<p style="text-align: center; font-weight: bold;">Receive good dental care</p>	<p style="text-align: center; font-weight: bold;">Spend less time in the hospital</p>

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### English and Spanish

<p style="text-align: center; font-weight: bold;">Goal Cards For Families</p>	<p style="text-align: center; font-weight: bold;">Tarjetas de metas para las familias</p>
<u>English Version</u>	<u>Spanish Version</u>

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**Manual**

- Additional questions to help families clarify their goals
- Resources to get started



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**Without Goal Cards** 

"Goal setting often feels like an exercise in 'reverse engineering' goals to simply justify a product or service... In order to purchase something with the [CLTS] waiver...our new case worker, she's always like, 'Well, what would be the goal for purchasing that?'"

~ Frustrated Parent

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**With Goal Cards** 

"[The nurse] brought out the goal cards and it was a really positive experience...It was neat to have someone sort and make piles with [child]. It was tactile...and it was neat to see the ones she picked versus the ones I imagined she would pick."

~ Pleased Parent

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## Engaging Children and Youth

In every environment in which we used the goal cards, parents mentioned that they were surprised to learn that their child had goals that they were not aware of.

Many parents identified goals that they had not thought of previously.

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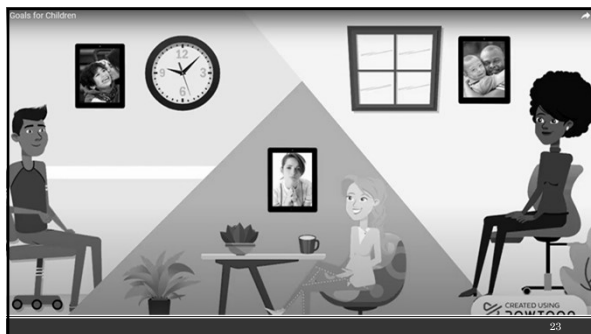
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CREATING GOALS FOR CHILDREN

Which categories of goals are you interested in considering? (Select all that apply)

Communication (4 example goals)




Community, Social, and School (9 example goals)

Home and Family (9 example goals)

Independence (6 example goals)

Medical and Health (11 example goals)

All of the above (39 example goals)

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**Be part of my school**

Yes, I am interested in this goal.

No, I am not interested in this goal.

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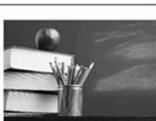

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**Be part of my school**

What school activities would you [your child] like to be more involved in? (Check all that apply)

Mainstream classes

Having lunch with other school mates

Before/After school activities

Something else

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**Be part of my school**



What supports are needed in order to participate more fully?  
(Check all that apply)

An identified peer buddy

A paraprofessional aide

A nurse

Something else

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What programs ask you to set goals?

Birth to 3 Program (Individualized Family Service Plan [IFSP])

Special Education Program (Individualized Education Program [IEP])

Medical Providers (Shared Plan of Care [SPoC])

Children's Long-Term Support (CLTS) Waivers (Individual Service Plan [ISP])

Other

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Your results are available in a few different formats.

1. The goals you selected.
2. The goals you selected with resources.
3. The goals you selected with action steps.
4. The goals you selected with resources and action steps.



**Goals**      **Goals and Resources**      **Goals and Action Steps**      **Goals, Resources and Action Steps**

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**Creating Goals for Children**  
goalsforchildren.wisc.edu

Date: \_\_\_\_\_  
Name: \_\_\_\_\_

Programs that support children with special health care needs or disability ask families and children to create goals.

You indicated that your family is asked to create goals for the following programs:

- **Special Education Program (Individualized Education Program [IEP])**
- **Children's Long-Term Support (CLTS) Waivers (Individual Service Plan [ISP])**

This tool helps families and children select goals. Below are the goals selected. Now it is the hope that programs supporting this child/youth can find ways to achieve these goals.

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**Goals Selected**



You selected a goal: **Be part of my school.**

- You indicated these are the areas to consider:
  - **Having lunch with other school mates**
  - **Before/After school activities**
  
- You [your child] may benefit from: **A paraprofessional aide.**

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**Goals Selected cont.**



**Resources:**

- Here are two articles you may be interested in:
  - [Including All Children: Health for Kids with Disabilities.](#)
  - [10 Reasons to Support Inclusive School Communities for ALL Students.](#)



**1 2 3 Action Steps:**

- Special education programs. School staff can offer suggestions and opportunities for students to be more engaged in the school's activities.

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### Initial Reactions

"I think these are fantastic! They are an easy way to identify goals and to help generate new ideas for goals!"

"The site was well done, easy to follow, and complete. It didn't take a ton of time so I believe parents really can complete this within their schedules and not be another burden. I think the concept is wonderful!"

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### Evaluation

- Survey at the end of the online application
- Feedback from Complex Care Programs
- Piloting with CLTS Waivers
- Two systems, one child
- Three systems, one child

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### Every Entity Needs the Family/Child to Create Goals

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## Wisconsin

- 120,000 children in **Special Education** (421 public school districts)
- 5,175 children in **Birth-to-Three**
- 12,000 children served by **Medicaid Waivers** (72 counties and 11 tribal nations)
- 1,000 children with medical complexity in three **Complex Care Programs**



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## Professionals

- How to support families who bring goals to a meeting.
- How to take a general goal and customize it for services and supports your program can provide.
- How to support families with goals not directly met by your program.



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## Next Steps

- Keep listening to families
- Collaborate with providers
- Spread across Wisconsin
- Spread across the U.S.A.



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**Example 1**

12-year-old female who had congenital CMV infection

- spastic quadriplegic CP, intellectual disability, seizure disorder
- obstructive sleep apnea, dysphagia with aspiration risk
- dependence on gJ-tube feedings
- frequent UTIs

Lives with mom and stepdad

- Mom with associate's degree, new full-time job
- Stepdad works nights at a 24-hour fitness facility

Attends school and receives therapies

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**Telemedicine visit**

Discussed

- Respiratory status
- UTIs
- GJ tube feeds
- Medications
- COVID-19
- Etc.

Mom had reviewed goal cards before visit

Her #1 goal for her daughter...

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**Play more**



Community, Social, and School

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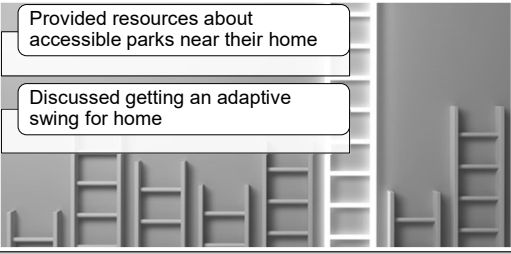
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Goals and Action Steps

Provided resources about accessible parks near their home

Discussed getting an adaptive swing for home



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Example 2

10-year-old male with an unusual chromosomal aberration

- Moderate-severe intellectual disability, nonverbal
- Severe esophagitis, many GI symptoms, procedures and meds
- Challenging behaviors, sleep disturbance

Lives with mom, stepdad, little brother

- Mom is a school secretary
- Stepdad works second shift, airport baggage handler

Attends school and receives therapies

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In-person clinic visit

Discussed

- Sleep
- GI symptoms and g-tube feeds
- Medications
- COVID-19
- Etc.

Mom sorted through goal cards during visit

Goals she chose for her son...

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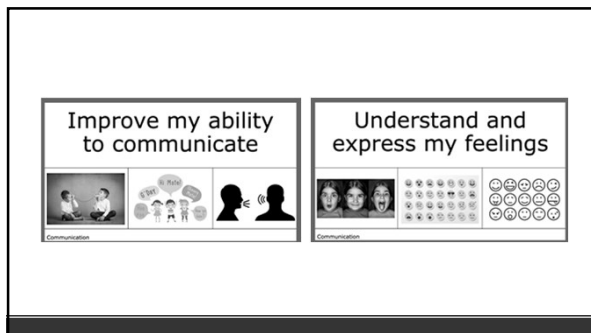
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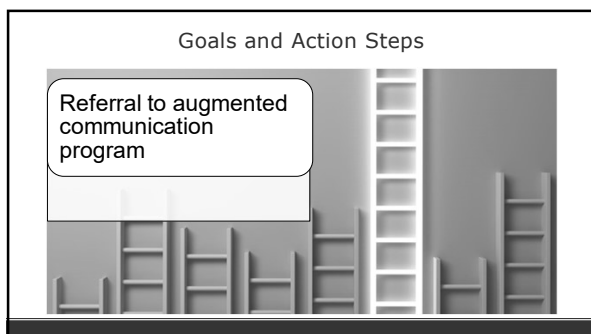
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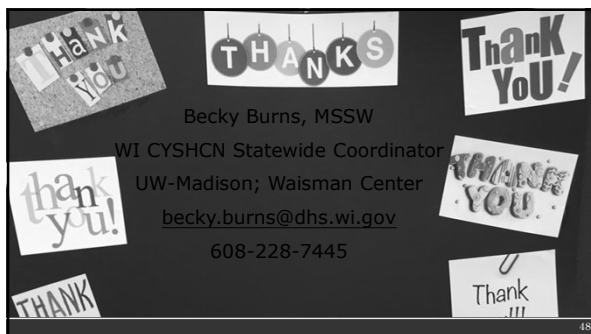
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