

Supporting Children with Medically Complex Conditions

Overview of Medical Support Needs

Vested Interest Statement

I have no real or perceived relevant financial relationships to the content of this presentation.

Objectives

- Review the goals and focus areas of supporting children and adults with medically complex conditions
- Review TSM eligibility for children with medically complex conditions
- Review of Resources for Supporting Individuals with Medically Complex Conditions”
- Review of Case Study

Why is This Important ?

Children need loving and caring adults and relationships to grow and develop to their fullest potential!

Goals:

Improve supports to families (birth, adoptive, foster) so that children can grow to full adulthood living at home with a bond to a loving adult.

Create family-based alternatives so that children who cannot live with birth families can grow to adulthood living in an alternative home with a bond to a loving adult.

Children with Medical Complex in PA

Mercer Analysis (2019 claims data)

- 240 children with medically complex conditions in congregate settings
- 2,709 children with similar diagnostic profiles in community settings
 - 1,380 of these children used more than 120 hours of home health services annually
 - 448 children enrolled for Pediatric Extended Care Center (PECC) services in 2018
 - PECC are child daycare centers that specialize in the support of children with medical complexities. May also be referred to as a PPECC(Prescribed Pediatric Extended Care Center)

Three Focus Areas

1. Provide children living in facilities with the opportunity for family life

- Budget and plan for children to transition to the family home
- Family Facilitator to transition children
- Expand and improve HCBS services to support them
- Develop Life Sharing for children who cannot go home with family

2. Ensure the health and welfare of children in facilities

- Regulatory changes and regulatory compliance guidance for inspections for facilities serving children with medical complexities
- Enhance licensing inspection teams with nurses and trained staff
- Provide technical assistance, training to support agencies

3. Strengthen services to families with children with medically complex conditions needs through age 21

- Register all eligible children with county ID/A agencies
- Improve coordination and delivery of physical health services including skilled nursing
- Expand and customize the ODP HCBS waiver to include children with complex care needs, ages birth - 21

Targeted Support Management Eligibility

- Eligibility criteria for TSM webcast: "Understanding and Implementing the Targeted Support Management Bulletin" is available to Providers, SCOs, and AEs on MyODP:

<https://www.myodp.org/course/view.php?id=1921>

- Eligibility requirements for medically complex conditions
- For eligibility criteria information related to ID, Autism or Individuals 8 years and younger with Developmental Disabilities please refer to the TSM bulletin or the above webcast.

Note: Effective 6/1/2022, eligibility in the Intellectual Disability and Autism (ID/A) waivers was expanded to include children with a developmental disability due to a medically complex condition.

TSM Eligibility for Children with MCC

To be considered for the TSM services, the child must:

1. Have a medically complex condition defined as one or more chronic health conditions that meet both of the following:
 - affect three or more organ systems; and
 - require medically necessary nursing intervention to execute medical regimens to use technology for respiration, nutrition, medication administration or other bodily functions;
2. have substantial adaptive skill deficits in three (3) or more areas of major life activities
3. Be age 0-21
4. Be recommended for an ICF/ORC level of care based on a medical evaluation.

TSM Eligibility for Children with MCC

DP 1090

- indicates the child
 - has a complex medical condition that effect **three** (3) organ systems and
 - requires medically necessary skilled nursing intervention to execute medical regimens
- must be completed by a licensed physician, physician's assistant, or certified registered nurse practitioner



pennsylvania
DEPARTMENT OF HUMAN SERVICES
OFFICE OF DEVELOPMENTAL PROGRAMS

Supplement to the Medical Evaluation
Level of Care Evaluation for Individuals with Complex Medical Conditions

INDIVIDUAL'S NAME:		DATE OF MEDICAL EXAM:	
ADDRESS:		DATE OF BIRTH:	

PRIMARY DIAGNOSIS:	ICD-10
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List all Chronic Medical Conditions that individually or in combination require medically necessary interventions such as medications, treatments, therapies, or adaptive equipment or technologies. Include ICD-10 code and the organ systems that are impacted by the diagnosis (or applicable updates).

CHRONIC MEDICAL CONDITIONS	ICD-10 CODE	ORGAN SYSTEM
o. (Sample) Asthma	J44.9	H
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

Please indicate on the above chart those organ systems impacted by entering the letter that corresponds to the organ system.

A. Cardiovascular	D. Integumentary	G. Reproductive	J. Urinary
B. Digestive	E. Muscular	H. Respiratory	
C. Endocrine	F. Nervous	I. Skeletal	

YES NO Does the individual require medically necessary skilled nursing intervention to execute medical regimens to use technology for respiration, nutrition, medication administration or other bodily functions including but not limited to tracheostomies, ventilators, central lines, parenteral nutrition, gastrostomy, jejunostomy, enteral feedings, dialysis, routine blood work monitoring, mobility equipment, or wound care?

IF YES, LIST MEDICALLY NECESSARY INTERVENTIONS:

PHYSICIAN'S SIGNATURE:	LICENSE NUMBER:
PRINTED NAME OF PHYSICIAN:	DATE:
PHYSICIAN'S ADDRESS:	PHYSICIAN'S PHONE NUMBER:

DP 1090 - 2022

TSM Eligibility for Children with MCC

Chronic Medical Condition:

- Is expected to last 1 year or more;
- Requires ongoing medical treatment;
- Limit activities of daily living; and
- Requires medically necessary interventions such as medications, treatments, therapies, or adaptive equipment or technologies.

Organ System: A group of tissues or organs that participate in the same major systemic activity, e.g., circulation or digestion

A. Cardiovascular	D. Integumentary	G. Reproductive	J. Urinary.
B. Digestive	E. Muscular	H. Respiratory	
C. Endocrine	F. Nervous	I. Skeletal	

TSM Eligibility for Children with MCC

Technology means the use of a medical device to support or replace a vital body function

Tracheostomy	Central line	Insulin pump
BiPAP/CPAP	Total Parenteral Nutrition	Blood Work Monitoring
Ventilator	Gastrostomy	Dialysis
Continuous Oxygen	Jejunostomy	Ostomy
Wound care	Enteral feedings	Mobility equipment

TSM Eligibility for Children with MCC

Example DP 1090 Chronic Medical Conditions

CHRONIC MEDICAL CONDITIONS	ICD-10 CODE	ORGAN SYSTEM
o. (Sample) Asthma	J44.9	H
1. Spina Bifida, unspecified	Q05.9	F
2. Congenital hydrocephalus, unspecified	G91.9	F
3. Neuromuscular dysfunction of bladder, unspecified	N31.9	J
4. Arnold-Chiari Syndrome with Spina Bifida and hydrocephalus	Q07.02	F
5. Acute and Chronic Respiratory Failure	J96.2	H
6. Tracheostomy status	Z93.0	H
7. Dependence on ventilator	Z99.1	H
8. Other Dysphagia	R13.19	B
9. Gastrostomy	Z43.1	B
10. Paraplegia, complete	G82.22	F

TSM Eligibility for Children with MCC

Example DP 1090 medically necessary skilled nursing interventions

<input checked="" type="checkbox"/> YES <input type="checkbox"/> NO	Does the individual require medically necessary skilled nursing intervention to execute medical regimens to use technology for respiration, nutrition, medication administration or other bodily functions including but not limited to tracheostomies, ventilators, central lines, parenteral nutrition, gastrostomy, jejunostomy, enteral feedings, dialysis, routine blood work monitoring, mobility equipment, or wound care?
IF YES, LIST MEDICALLY NECESSARY INTERVENTIONS: Tracheostomy, Ventilator, Gastrostomy, enteral feedings, Intermittent urinary catheterization, Braces, wheelchair	

Adaptive Functioning

- Adaptive skills deficits are determined by either the Vineland Assessment or the ABAS assessments that indicate substantial adaptive skill deficits in **three** (3) or more areas of major life activity:
 - » self-care,
 - » learning,
 - » communication,
 - » mobility,
 - » self-direction and/or
 - » capacity for independent living

TSM Eligibility for Children with MCC

MA-51 form

- document that the individual is recommended for an ICF/ORC level of care completed by a licensed physician, physician's assistant, or certified registered nurse practitioner.

20A PHYSICIAN'S RECOMMENDATION	To the best of my knowledge, the patient's medical condition and related needs are essentially as indicated above. I recommend that the services and care to meet these needs can be provided at the level of care indicated - check <input checked="" type="checkbox"/> only one				
<input type="checkbox"/> Nursing Facility Clinically Eligible Services to be provided at home or in a nursing facility	<input type="checkbox"/> Personal Care Home Services provided in a Personal Care Home	<input type="checkbox"/> ICF/ID Care Services to be provided at home or in an Intermediate care facility for the intellectually disabled	<input checked="" type="checkbox"/> ICF/ORC Care Services to be provided at home or in an Intermediate care facility for consumers with ORCs	<input type="checkbox"/> Inpatient Psychiatric Care	<input type="checkbox"/> Other (Please Specify) _____

Process to Transition Children with MCC to Home

The process of transitioning a child with medical complexity conditions from a pediatric facility requires:

- A team of individuals
- Excellent communication
- Collaboration between all members of the team
- Coordination of services across various program offices and providers

Transition Teams

Transition Teams may include but are not limited to:

- The child and their family or caregiver (guardian/custodian)
- Administrative Entity representative
- Supports Coordinator
- MCO Special Needs Unit case manager
- Pediatric Residential Providers social worker/discharge coordinator
- Family Facilitator
- Medical Team including skilled nursing supervisor, DME
- Mental health case worker/behavioral supports specialist
- Educational contact
- Early Intervention contact
- Provider representatives

AE Referral Information to be sent to SCO

Referral should include:

- DP 1090
- MA-51
- Plan documents – residential plans such as medical plans, clinical notes and/or the individual support plan from the residential facility
- Guardianship documents
- Surrogate Health Care Decision Maker/Health Care Representative if applicable
- Evaluations and assessments
- Contact information for the MCO Special Needs Unit Case Manager and if possible other transition team members
- Upcoming team meetings if scheduled

Process to Transition Children with MCC Home

Important things to remember:

- This is a new process for everyone involved.
- Not all members of the team become involved in the transition at the same time and actions may have already been initiated. Therefore, communication between team members is of vital importance when a new member joins the team.
- Participation in team meetings is essential and should include a discussion and understanding of each members roles and responsibilities.
- The SC should reach out to the MCO Special Needs Unit case manager prior to meeting with the family.
 - Signed consent is not required for this contact or contact with other Transition team members.

Development of ISP and Monitoring

- Referral information provided by AE, including medical records, and information gathered from the child, family/caregiver and/or staff, should be used by the SC and team members when developing the ISP.
- The transition team should be invited to the ISP meeting.
- ISPs should be updated to reflect current medical information gathered by the SC during the ISP monitorings.
- Communication between providers, SC's and other team members is essential

Resources to Assist in Supporting Children with MCC

ODP is developing a variety of resources that will assist in supporting children with MCC. These resources will be available on the MyODP website and will include:

- An Introductory Guide to Supporting Individuals with Medically Complex Conditions which will include:
 - An educational section on the basic functioning of the organ systems of the body.
 - Reference material containing special consideration that are needed when supporting child with MCC.
 - A glossary of frequently used medical terms
 - A list of reliable resources for additional information
 - Online resources and other supports
 - Case studies
- A series of recorded webinars on specific topic areas related to medical needs have been recorded and are available.

Example from the Introductory Guide:

Overview of Body Systems

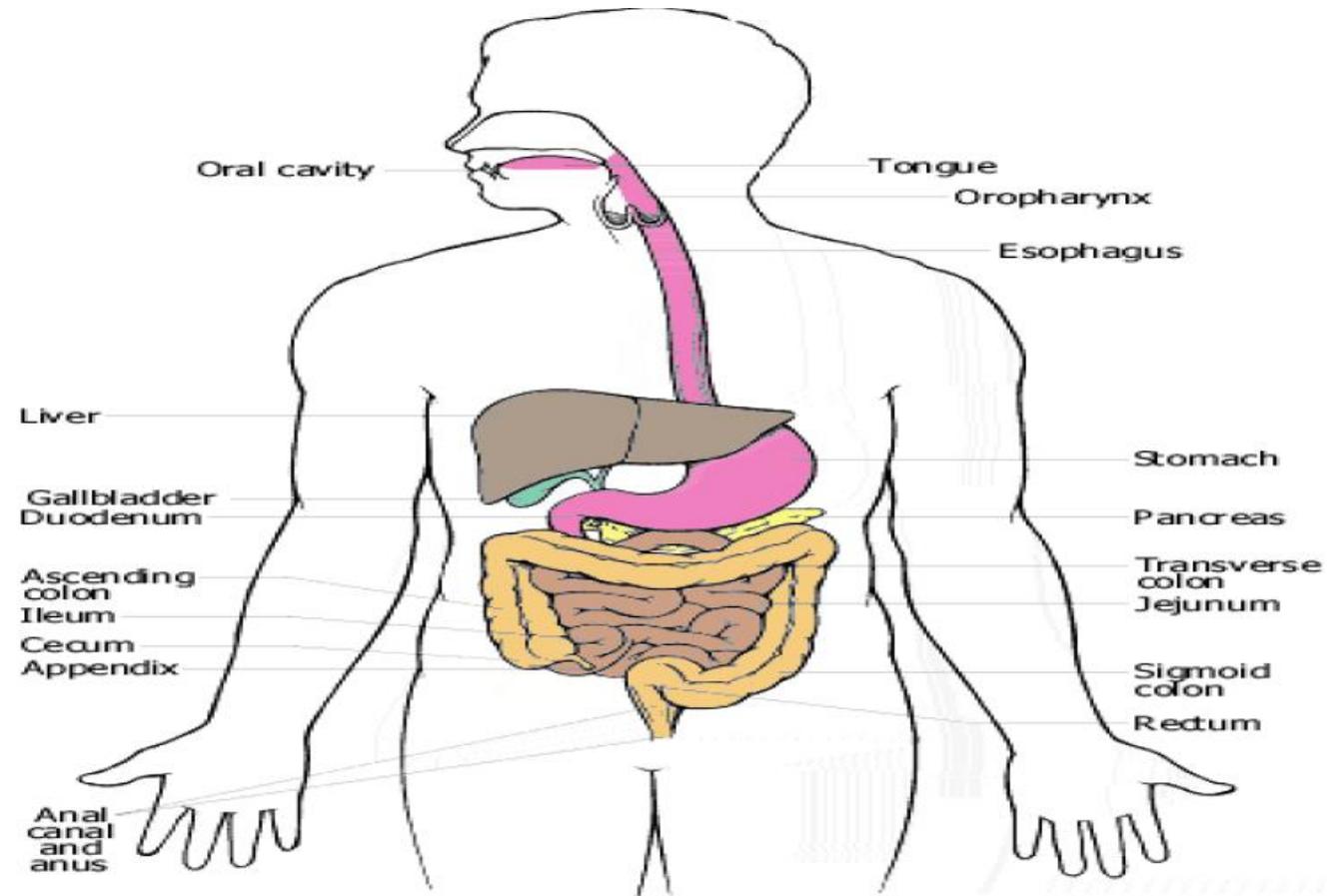
Information about body systems and their functions, common diseases of body systems and what to document about the body systems can be found here.

The Digestive System (Gastrointestinal Tract)

Function: The Digestive system includes the mouth, esophagus, stomach, liver, pancreas, gall bladder, large and small intestines and rectum. All of these organs work together to process food that is eaten and to eliminate waste products. The food is chewed in the mouth and then is moved down through the esophagus to the stomach.

Introductory Guide to Supporting Individuals with MCCs

Illustration of the Digestive System



Introductory Guide to Supporting Individuals with MCCs

Disorders Associated with the Digestive System:

- **Gastrointestinal Reflux Disorder (GERD)**- return of gastric contents to the esophagus
- **Peptic and Duodenal Ulcers** -ulcerations in the wall of the stomach and small intestine
- **Constipation**-passage of infrequent, hard, difficult bowel movements
- **Irritable Bowel Syndrome** -Disorder that causes abnormal function of the large intestine and causes cramping and bloating. It is sometimes referred to as colitis or spastic colon.
- **Intestinal obstruction**- blockage of the bowel

Introductory Guide to Supporting Individuals with MCCs

Documentation

Clinical documentation should include

- Diagnoses or condition the child may have related to the digestive system
- Any dietary restrictions or special diets
- Use of tube feedings – care and maintenance of the equipment and supplies. Emergency equipment and contact information.
- Normal bowel pattern –ordered bowel program details

Specific Considerations for Children with MCC

example:

Providing Nutrition To a Child Through a Feeding Tube

- Some infants or children are not able to eat food or properly absorb nutrients from ingested food, so in order to obtain the nutrition they need a tube must be placed through their belly into their stomach or intestines.
- These tubes maybe referred to as
 - feeding tubes, Gastrostomy tubes (G-tubes), Jejunostomy tubes (J-tubes), PEG tubes, Mic-key buttons, or other names.
- Formula (called Enteral Feeds) or blenderized foods are then delivered directly into their stomach or intestines through this tube using a machine called a feeding pump.

Specific Considerations for Children with MCC

Providing Nutrition To a Child Through a Feeding Tube

cont.

- The child-specific plan must include:
 - Type of feeding tube used
 - Type of feeding or formula to be used.
 - Volume, duration and how the feeding is to be administered
 - Optimal positioning during feedings to prevent aspiration
 - Periodic maintenance and/or calibration of the feeding pump consistent with manufacturer's instructions to ensure proper mechanical functioning.
- Staff/caregiver knowledge
- Emergency plan to address complications or issues

Specific Considerations for Children with MCC

Example:

– Emergency Plan for Feeding tubes

- Are the staff/caregivers knowledgeable about possible complications or emergencies related to the feeding tube?
 - Such as: Reddened skin and/or pain around the area the tube enters the belly, fluid leaking from the hole where the tube enters, fever, swelling or redness around the hole the tube enters which may be a sign of an infections, bleeding from the hole the tube enters, accidental removal (dislodging) of feeding tube. Severe belly pain, blotted belly which are indications that the feeding tube has moved in the individual's body so that it may no longer be in the stomach and/or intestines but somewhere else in their body?
- Are staff/caregiver knowledgeable about what to do in the case of an emergency with the feeding tube?
 - Are Emergency contact information posted and readily available for the staff?
 - Are emergency supplies available and accessible? Is there a policy or procedure to routinely check that the emergency supplies are available and accessible?

Glossary of Frequently Used Medical Terms

- **Gastrostomy Tube:** a tube inserted through the belly that brings nutrition directly into the stomach. Also known as a G-tube.
- **Jejunostomy Tube:** a tube surgically inserted through the belly that brings nutrition directly into the child's small intestines. Also known as a J-tube.
- **Insertion Site:** a hole in the child's skin that the surgeon makes to insert the gastrostomy tube into the child's stomach.
- **Constipation:** When an individual passes less than three bowel movements a week, or has infrequent, hard or difficult to pass stool.
- **Bowel Movement:** movement of stool (the undigested food and solid wastes from the body) through the intestines and out of the body.

MyODP Website: Recorded Webinars

The recording of the educational webinars provided by ODP related to the Children and Individuals with Medical Complexities are housed on the MyODP Website. Webinars include:

- **AE changes to TSM, Supporting Individuals with Medical Complexities** presented by ODP Deputy Secretary, Kristin Ahrens
- **Medical Overview** presented by Dr. Gregory Cherpes and Rhonda Gengler, RN
- **Respiratory Assistance** presented by Southwestern HCQU & Michelle Blake RN
- **Nutritional Intake Assistance** presented by Western HCQU
- **Skin Care & Elimination Assistance** presented by Northeastern HCQU and Audrey Wicks RN
- **Developmental Support** presented by Northwestern HCQU
- **Infection Control** presented by Rhonda Gengler RN

Online Resources for Children with MCC

Recommendations and examples for resources for medical information on diseases and conditions

- [Ask CDC - Diseases & Conditions | CDC-INFO | CDC](#)
- WebMD, <https://www.webmd.com/>
- Children Hospitals websites such as –
 - Children’s Hospital of Pittsburgh, <https://www.chp.edu/for-parents/health-tools/disabilities/medical-references/disease-condition>
 - Children’s hospital of Philadelphia, <https://www.chop.edu/conditions-diseases>
 - Cleveland Clinic Children’s, <https://my.clevelandclinic.org/pediatrics/health>
 - Mayo Clinic, <https://www.mayoclinic.org/patient-care-and-health-information>
- Disease or condition specific organizations –
 - Spina Bifida Association, <https://www.spinabifidaassociation.org/what-is-spina-bifida-2/>
 - Rare Disease Association, <https://rarediseases.org/>

Online Resources for Children with MCC

Recommendations for resources for standards of care:

- The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) at <http://www.nutritioncare.org/>
- CDC Guidelines for the prevention of intravascular catheter-associated bloodstream infections.” at <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5110a1.htm?vm=r>
- Guidelines for Prevention and Management of Pressure Ulcers (injuries)” from the Wound, Ostomy and Continence Nurses Society (WOCN).
- The American Association for Respiratory Care, Clinical Practice Guidelines. <http://www.aarc.org/resources/clinical-resources/clinical-practice-guidelines/>

Additional Supports for MCC

Resources for children & adults with MCC

- ODP Regional Office Nurse staff
- Health Care Quality Units
- Skilled Nursing staff
- MCO Special Needs Unit case managers

Resources specific to children

- Office of Medical Assistance - EPSDT information/services
- OCYF resources
- Family Facilitator

Reach out to the ODP Regional Office staff for the contact information for the above listed supports.

Case Study: Patel

Patel is a 14-year-old child born on 4/15/2008.

He is a happy and friendly young man who loves playing video games, using his iPad, iPhone, board games, listening to music and bowling. He also loves socializing with his school mates and visiting with his aunt and cousins.

Patel resided in a pediatric residential facility. His mother passed away from a drug overdose and his father is incarcerated and lost all parental rights. His paternal Aunt Cassie has custody.

Case Study: Patel

Patel's Medical Diagnoses include:

- Spina Bifida,
- Hydrocephalus
- Ventricular Peritoneal (VP) shunt,
- Arnold-Chiari Syndrome,
- Chronic Respiratory failure,
- Tracheostomy,
- Ventilator dependent while asleep
- Dysphagia,
- Gastrostomy tube,
- GERD(Gastroesophageal Reflux Disease)
- Seizure disorder
- Neurogenic bladder,
- Constipation,
- Paraplegia.

Case Study: Patel

Technology, medical equipment and skilled nursing interventions:

- Tracheostomy and supplies
- Ventilator, humidifier, portable suction machine, and supplies
- Pulse Oximeter and supplies
- Oxygen and supplies
- Gastrostomy tube and supplies
- Feeding pump
- Urinary catheter and supplies
- Wheelchairs –self propelled
- Hoyer lift for transfers
- Hospital bed
- Outside lift for entrance to home
- Bath/shower chair
- Modification to bathroom including accessible shower
- Skilled Nursing Services: 16hrs/day/7days
- Home Health Aid (HHA) 8 hrs/day

Case Study: Patel

- During a routine follow up call from the MCO Special Needs Case Manager, Patel and Aunt Cassie discussed their wish for Patel to move into Aunt Cassie's home.
- The MCO Special Needs Case Manager made a referral to the Family Facilitator.
- The Family Facilitator reached out to Patel and his aunt when she received the referral.
- Utilizing the Charting the Life Course tools, Patel and his aunt developed a plan for Patel's future.

Case Study: Patel

- It was determined that
 - Aunt Cassie's home needed modification for Patel to safely live in the home.
 - Aunt Cassie and another family member also needed to learn to care and support Patel due to his medically complex conditions.
- The Family Facilitator assisted Aunt Cassie in reaching out to county ID office to register Patel.
- Referral information was sent to the SCO by the AE.

Case Study: Patel

- A team meeting was set up with the members of the transition team prior to the SC reaching out to Patel or his aunt.
- During this meeting, the following occurred:
 - Introduction of team members and their roles and responsibilities
 - Reviewed actions that were initiated.
 - Scheduled ISP meeting
- Actions initiated
 - Family Facilitator has been working with the residential facility to arrange training for the aunt and other caregiver.
 - An OT/PT assessment was completed by the residential facility at the aunt's home to determine what modification were needed, and a letter of medical necessity was completed for the modifications. The modifications were initially denied by the MCO.
 - Additional supporting information was added to the request and the identified modifications were approved.

Case Study: Patel

- The home needed a lift to allow Patel to enter and exit the home safely with his wheelchair and other medical equipment. Renovations to access his bedroom were also needed, these modifications were funded by the MCO.
- Due Aunt Cassie health issue, it was determined additional support would be need for Patel by Home Health Aid services.
- Skilled nursing, physical therapy, and transportation was needed due to his medically complex conditions.

Case Study: Patel

Patel's DP 1090 Chronic Medical Conditions

CHRONIC MEDICAL CONDITIONS	ICD-10 CODE	ORGAN SYSTEM
o. (Sample) Asthma	J44.9	H
1. Spina Bifida, unspecified	Q05.9	F
2. Congenital hydrocephalus, unspecified	G91.9	F
3. Neuromuscular dysfunction of bladder, unspecified	N31.9	J
4. Arnold-Chiari Syndrome with Spina Bifida and hydrocephalus	Q07.02	F
5. Acute and Chronic Respiratory Failure	J96.2	H
6. Tracheostomy status	Z93.0	H
7. Dependence on ventilator	Z99.1	H
8. Other Dysphagia	R13.19	B
9. Gastrostomy	Z43.1	B
10. Paraplegia, complete	G82.22	F

Case Study: Patel

- The DP1090 indicates that the Chronic Medical Conditions affect the following organ systems
 - Digestive,
 - Nervous,
 - Respiratory, and
 - Urinary systems.
- The sections of the Introductory Guide to Supporting Individuals with MCCs that pertain to the above organ systems were reviewed.

Case Study: Patel

Patel utilizes the following technologies, medical equipment and treatments

- Tracheostomy and supplies
- Ventilator, humidifier, portable suction machine, and supplies
- Pulse Oximeter and supplies
- Oxygen use PRN
- Gastrostomy tube feedings with feeding pump
- Intermittent Urinary catheter
- Bowel Program
- Wheelchairs –self propelled
- Hoyer lift for transfers
- Hospital bed

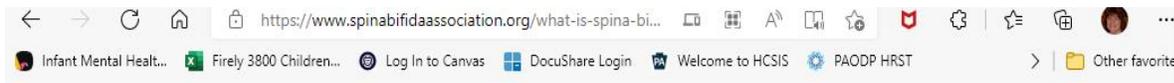
Case Study: Patel

Specific considerations for children with MCC sections that pertain to Patel were:

- Respiratory Assistance
 - Tracheostomy
 - Ventilator use
 - Oxygen use
 - Monitoring
- Nutritional Assistance
 - Dysphagia
 - Feeding Tubes
- Elimination Assistance
 - Intermittent Urinary Catheterization
 - Bowel Programs
- Skin Care
 - Mitigating risk of skin issues
- Infection Prevention and Control
- Developmental Support

Case Study: Patel

The SC was not familiar with Spina Bifida, so educational information from the Spina Bifida Association web site was reviewed.



Menu



<https://www.spinabifidaassociation.org/what-is-spina-bifida-2/>

Case Study: Patel

A team meeting was held to discuss discharge and home modifications.

- Modifications to home were completed except for bathroom modification.
- MCO Special Needs Case Manager reached out to skilled nursing agencies and a provider was found to provide the skilled nursing and the additional Home Health Aid support needed by the aunt when nursing is not present in the home.
- Request for DME supplies were denied the first time the request was made, but a new letter of medical necessity and corresponding documentation was provided, and approval was granted.
- Issues with DME supplies/equipment and staff were worked out.

Case Study: Patel

A year after the Family Facilitator received the referral, Patel was discharged from the residential facility to his aunt's home.

ISP Development

- During the initial ISP meeting, all transition team members were invited to attend the meeting including the nursing staff and MCO case manager
- Encouraged all team members to ask questions if they were unfamiliar with any aspect of the plan or Patel's support and care needs

Case Study: Patel

Like and Admire - What do people like and admire about the individual?:

- Patel has a happy and friendly personality. He is admired for his strong-willed nature. Patel loves to socialize with others. He has overcome a lot of adversities in his life.

Know and Do

What does the consumer/family think someone needs to know to provide support?

- Patel is 14 yrs old and lives with his paternal aunt in her private home. He receives targeted support management with support coordination.

Case Study: Patel

What does the consumer/family think someone needs to know to provide support? Cont.

- Patel requires skilled nursing services 16 hours a day, 7 days per week from 11pm to 7am and 7am to 3pm to ensure that his medically complex conditions are addressed as per his medical/nursing plan.
- Patel also requires HHA support 8 hours day, 7 days per week from 3pm to 11pm and when skilled nursing services are not provided. These services are needed to assist Patel's aunt in his care and support.
- Patel needs to have his Passy-Muir Speaking Valve on his tracheostomy to communicate verbally

Case Study: Patel

What does the consumer/family think someone needs to know to provide support? Cont.

- Patel attends Pioneer School during the regular school year and will participate in the extended school year program. Patel receives PT and OT services twice a week while at school. Skilled nursing services are provided for transportation to and from school and while at school.
- Patel has multiple medically complex conditions. Staff and caregivers should refer to the Nursing Plan of Care for details related to his care and treatment.

Case Study: Patel

What does the consumer/family think someone needs to know to provide support? Cont.

- Patel has difficulty breathing through his nose and his mouth, so he has a tracheostomy. This is a tube placed in a hole in his neck. The tube goes through the hole into his windpipe which leads to his lungs.
- Patel need assistance breathing when he sleeps. This assistance is provided from a machine called a ventilator.
- The ventilator helps Patel take breaths by pushing air and/or oxygen into his lungs. Ventilators are very complicated machines, which require frequent monitoring to ensure they are functioning properly.
- The ventilator also has safety alarms that will sound if there is an issue with it's functioning.

Case Study: Patel

What does the consumer/family think someone needs to know to provide support? Cont.

- If the tracheostomy is pulled out, blocked, or clogged with mucous or the ventilator becomes disconnected, fails to function properly, or shuts down while in use. Patel may not be able to breath. These events may prevent him from receiving enough oxygen in his blood. The lack of oxygen may cause permanent damage to Patel's brain, or other parts of their body and may lead to death.
- **This is a life-threatening emergency.**
- An Emergency Plan is necessary for any technology or medical equipment that is needed to sustain life. Such as a tracheostomy or ventilator

Case Study: Patel

What does the consumer/family think someone needs to know to provide support? Cont.

- Patel's tracheostomy and ventilator needs to be monitored and cared for provided by a licensed health care practitioner or a trained family member who has been authorized to do so by the health care provider.
- Direct Support Professionals are not permitted to perform skills that are required to be provided by a nurse or a trained family member such as the monitoring or the care of the tracheostomy or the ventilator.
- The skilled nursing staff or trained family member must be available at all times.

Case Study: Patel

Important to

- Should include social activities even if they may require adaptations to accommodate Patel's medically complex conditions.

What Makes Sense

- Patel needs to always have his emergency equipment and contact information with him.
- Patel's tracheostomy and ventilator needs to be monitored and cared for provided by a licensed health care practitioner or a trained family member who has been authorized to do so by the health care provider.
- Patel needs to participate in enjoyed activities and socialization.

Case Study: Patel

Medical Information

Collaboration with the nursing staff is important for this section of the ISP. MCO Special Needs Unit Case Manager may also have contributions for this section.

- **Medications**

- Complete medication section of the ISP including all prescription medications, over the counter medication and nutritional supplements.
- The diagnosis or reason for the medication or supplement and any special instructions/precautions should be noted.
- The use of one pharmacy should be encouraged to mitigate the risk of drug-to-drug interactions.

- **Allergies**

- All allergies including medication, food and environmental ones should be included. A Latex allergy is very common with individuals who have Spina Bifida

Health Evaluations & Medical contacts

Patel's Medical Providers and contact information was identified. Providers included:

- Primary Care Physician
- Neurologist
- Neurosurgeon
- Pulmonologist
- Otolaryngologist (ENT)
- Urologist
- Orthopedic Surgeon
- Gastroenterologist
- Physical/Occupational Therapists
- DME company
- Skilled Nursing/Home Health Agency

Current Health Status

- List current and new diagnoses
- Visits to Emergency rooms, urgent care facilities or hospitalizations
- The last appointments with the medical providers were identified and any follow up appointments were confirmed.
- Orders for diagnostic procedures, blood work or other medical procedures were reviewed and confirmed. Transportation needs are confirmed.
- Review the Introductory Guide to Supporting Individuals with Medically Complex Conditions for specific considerations for Patel's medically complex conditions.

Current Health Status: Example

- Patel had an ER visit on 2/3/2022 due to seizure activity that did not respond to PRN medication. Patel was evaluated and sent home the same day. Discharge orders were to monitor Patel's vitals hourly for 12 hours and contact his neurologist for a follow up appointment.
- Patel sees his PCP for his annual physical on 3/20/2022 his last physical was 4/1/2021. Accessible transportation has been arranged for this appointment. The skilled nursing staff and Patel's aunt will accompany him to this visit.

Case Study: Patel

Developmental Information and Psychosocial Information cont.

- Patel had a Psychological Assessment completed by the county Intermediate unit. He does not currently have a mental health diagnosis. A Behavioral Support Plan is not needed at this time.

Physical Assessment

- System Area and Descriptions should be completed and should include any special consideration as needed for Patel's medically complex conditions.
- Consultation with nursing staff and MCO case manager should be considered.

Physical Assessment:

- System Area: Nervous System
- Description: Patel was seen for increase seizure activity by his neurologist and the neurosurgeon. EEG was completed, a change in his seizure medication was prescribed. Patel's VP shunt was noted to be functioning without issues.

Immunization Booster:

- Complete as needed.
- Children have specific vaccination schedules.

Health and Safety: General Health and Safety Risks

- Information related to specific Chronic Medical Conditions such as protocols for Seizures
- Emergency plans for medical technologies used by Patel such as the tracheostomy and feeding tube.
- Strategies used during the crisis and after a crisis.
- Verification of the emergency plan, where and how to access it.
- Nursing plan must have a crisis support plan and it should be with the individual at all times.

Health and Safety: General Health and Safety Risks

- Patel relies on his tracheostomy to breath. The properly stocked Emergency Airway bag, oxygen tank and emergency contact list should be with Patel at all times.
- Local EMS and Hospitals should be notified of Patel's reliance on medical technologies.
- The Emergency plan and list of emergency contact information should be up to date and posted related to Patel's Tracheostomy, Ventilator and G-tube and other medical supplies and equipment. Staff and care givers should be knowledgeable of possible complications related to these technologies.

Health and Safety: Traffic, Cooking/Appliance use, Outdoor Appliance and Water Safety

- Patel is on Ditropan for his neurogenic bladder. One of the side effects of Ditropan can cause him to become overheated easily. This should be considered when he is out in hot weather. He should have water available to drink and a place to stay cool.
- Due to Patel's tracheostomy and the risk for water entering his lungs. He should not be immersed in water. Caution should be used when Patel showers or is in the bathtub.

Health and Safety: Knowledge of Self-Identifying Information and Stranger Awareness

- Patel must have his Passy-Muir Speaking Valve on his tracheostomy to speak.

Health and Safety: Sensory Concerns

- Patel has paraplegia. He cannot move or feel below his waist. This places Patel at a higher risk for the development of skin wounds.
- Patel must be repositioned, and his attends should be checked every two hours. His skin should be checked for wounds daily.

Health and Safety: Meals/Eating

- Patel has dysphagia. He cannot have anything by mouth.
- Patel received of his nutrition, fluids and most of his medications through his G-tube.
- Patel should be in an upright position or have his head elevated while he receives his G-tube feeding and for 30 minutes after the feeding.

Health and Safety: Supervision Care Needs

- Patel's tracheostomy and ventilator needs to be monitored and care should be provided by a licensed health care practitioner or a trained family member who has been authorized to do so by the health care provider at all times.
- Patel should be monitored with his Pulse Oximetry when he is not being directly observed.

Health and Safety: Is there a crisis support plan in place?

- Document back up plans for
 - Life sustaining equipment and treatments
 - Comprehensive Crisis support plan. - summarize the crisis or emergency plans
- Behavior support plan – How to avoid crisis situations and actions to be taken if a behavioral crisis occurs.
- Contingency Back up plans – for unavailable staff or family members

Health Promotion: Health condition/Issues

- Due to Patel's medically complex conditions, he is at a higher risk for developing an infection.
- Patel's living area should be clean. Staff should follow infection control practices such as: washing their hands or using hand sanitizer, the use of personal protective equipment (PPE) when needed, disposal of dirty supplies, routine cleaning and disinfecting of equipment, and disposing of soiled attends.
- Patel should be observed for signs of an infection

Case Study: Patel

Physical Development:

- Patel utilizes his wheelchair for mobility. Safety belt should be used at all times, while in the wheelchair to avoid sliding or falling out of his chair.

Adaptive/Self Help

- Patel requires assistance with his ADL's, but he should be encouraged to complete the activities included in his OT's plan.
- Patel requires 2-person assistance with transferring to the toilet and with completion the enema with his bowel program.

Case Study: Patel

Adaptive/Self Help

- Patel has a plan with the goal of independently performing his intermittent catheterization. Staff should refer to the plan while assisting Patel with his every 4-hour catheterization.
- The bathroom needed renovations so Patel can safely bath, which the SC is addressing. These renovations were not identified prior to his transition.
- Patel will require the use of a shower chair once the bathroom renovations are completed
- Patel is currently being washed in his bed and in the kitchen until his bathroom renovations are completed.

Case Study: Patel

Learning/Cognition

- Should include any special consideration as needed for Patel's medically complex conditions.
- Collaboration with the school district and review of the IEP should occur.

Communication

- Patel must have his Passy-Muir Speaking Valve on his tracheostomy to speak.

Social/Emotional Information

- Privacy should be maintained during all ADL's and medical procedures.

Case Study: Patel

Monitoring and updates to his plan of care and ISP:

- The frequency of ISP monitoring should be individualized according to the needs of Patel. After being transitioned to home, the SC made monthly monitoring visits.
- Coordination of care between the SC, Provider, MCO Special Needs Case Manager and Nursing provider and medical provider are essential in maintaining the appropriate care and supports.
- All involved stockholders should refer to the “Introductory Guide to Supporting Individuals with Medically Complex Conditions” and other resources to ensure all areas of care and support are being addressed.

Case Study: Patel

Monitoring and updates for Patel and Aunt Cassie:

- When the bathroom accessibility issue was identified during one of the SC monitoring visits, the SC started working with the family to obtain a new assessment of needs for access and to obtain an estimates for the necessary modifications.
- MCO explored what modification they may cover. Providers, AE and SC should be familiar with the MA state plans and processing for these requests for the identified modifications. There have been changes to these plans. Also, the providers, AEs and SCs should explored what other funding sources maybe available if the MA funding is denied.
- The SC provided the family with a list of contractors and request the estimates be sent directly to the SC.

Case Study: Patel

Challenges:

- SC turn over occurred and there was a need for the SC supervisor to provide additional support.
- Continued collaboration and communication between involved service providers to meet the needs of Patel and his family
- Knowledge deficit of what services could be provided by which funding sources were identified.
 - Encourage asking questions and exploring other funding opportunities
- Knowledge deficit of the required support and care for medically complex conditions were also identified and addressed.
- Ongoing issue with the Social Security office that the SC was able to assist the Aunt in resolving.

THANK YOU!

Thank You!!!!