Introduction to the Long Term Care Center

The Long Term Care Center at Children’s Specialized Hospital provides dignified and tender loving care for children and adolescents with long-term medical needs. Children’s Specialized Hospital opened the Center, the first hospital-based pediatric skilled-care facility in the state, to meet the special needs of New Jersey families.

The bright, inviting environment of the Long Term Care Center is designed by professional pediatric recreational specialists expressly for children. The therapeutic atmosphere coupled with specialized medical and nursing care and a diversity of activities is designed to maintain each child’s abilities and encourage the maximum potential in each child.

The Center’s carefully selected staff of very special individuals is devoted to the well-being of every child. These trained professionals are sensitive to the decisions faced by parents of a child for whom they can no longer care for at home or are transferring from a hospital or rehabilitation hospital. Experienced in helping families of long term care children, they assist and counsel parents who need to place their child into a total care environment.

Family involvement is strongly encouraged and flexible visiting hours are provided for all family members. The nursing staff maintains communication with parents regarding their child’s daily care.

Family involvement is very important to the child’s well-being. Family members are strongly encouraged to visit their child and participate in their care as often as possible.

The team assesses the needs of each child upon admission to the Long Term Care Center and prepares a comprehensive care plan to meet their needs. Continual monitoring of each child’s status assures that his or her care plan is adapted, thereby maximizing each child’s potential.

In addition to the core services provided, Children’s Specialized Hospital collaborates with each child’s school district to coordinate the needs of children who are eligible for these services.
Philosophy of the Long Term Care

We believe that every child is capable of personal growth and contributing to the world around them. Our mission is to harness our skills and resources including the power of families and community to help each child reach his or her full potential. We do this by:

- Appreciating that every child – no matter how disabled or dependent – deserves to be loved, treated with respect, and given the assistance and opportunity to control their lives to the extent possible.

- Helping our child maintain optimum health through attentive daily care, good nutrition, physical activity and an environment that is comfortable, clean and safe.

- Remembering that we care for each child’s mind and spirit, not just their body. We understand our child’s needs for companionship, social interaction, a sense of belonging, fun and mental stimulation.

- Acknowledging that each child is an individual, with their own unique needs, personal circumstances, background and right to privacy. We respect differences and aim to minimize the adverse effects institutional living can have on restricting personal liberty.

- Recognizing and respecting the role family plays in their child’s well-being, happiness and development. We encourage family to participate in their child’s direct care and the decisions impacting that care.

- Encouraging an open and mutually respectful dialogue between family, staff, school and medical professionals to allow for each perspective and increase the likelihood of best solutions.

- Partnering with parents to advocate for full education in the right setting based on the individual child’s needs.

- Creating opportunities for children to participate in community life and encouraging the community to play a greater role in the work we do.

- Ensuring that children are in the most appropriate setting to meet their needs. The length of stay for children is individually determined based upon enabling the child to reach their full potential.
Person- and- Family -Centered Care (PFCC)

Children’s Specialized Hospital practices Person- and- Family -Centered Care. To that end, we understand that a partnership with our families is essential in providing high quality care. Together, we can best plan your child’s care.

By practicing Person and Family-Centered Care

- We recognize the vital role that families play in ensuring the health and well-being of children and family members of all ages.
- We respect each child and family’s innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their care-giving and decision making roles.
- We understand that emotional, social and developmental support is integral components of health care.
- We recognize that Person- and Family-Centered Care leads to better health outcomes, as well as more satisfactory health care experience for your entire family.
- We recognize that families should be a partner in hospital decisions that may affect them.
- We understand that every child and family has the right to honest and unbiased information.
- We understand that every child and family should be respected and their cultural diversity honored.
Telephone Calls to the Long Term Care Center

We welcome your calls and are happy to share information about your child anytime. Please note that to insure your child’s care, safety and privacy there are phone call processes we have set up. If you call the main center number below and no one is available to answer it will be forwarded automatically to the Charge Nurse Phone. Should there be times, when all nurses are busy taking care of the children; the phone may be set to take a message. Once the nurses are free they will pick up and return calls from the message machine.

Long Term Care Telephone Number

Mountainside Center: 908-301-5450

Toms River Center: 732-797-3800
Visiting (Sharing) Time at the Long Term Care Center

Family involvement is very important to your child's well-being. Family members are strongly encouraged to visit their child as often as possible.

The following are sharing times for families and friends

- Daily 24 hours subject to reasonable clinical and safety restrictions and the resident’s wishes.
- Observance of sleep times and courtesy to all roommates is respectfully required.

Sharing Time Guidelines

- Parents/Guardians may be asked to visit in an area outside of their child’s immediate room if other children in the room would be disturbed or medical needs require.
- Parents/Guardians will be given a permanent id tag they must wear while sharing time with their child in the Long Term care Center.
- Visitors must sign in indicating who they are visiting and wear a visitor’s tag.
- Young children must be supervised by an adult at all times.
- People with colds, coughs, or other contagious illnesses are asked to stay home until they are well. We don’t want your child to get sick.
- Please let us know immediately if any recent visitor has visited and then become ill or been diagnosed with an illness or disease like chicken pox.
- Please look for special signs (stop signs) before entering the room. If you see a sign, please get information from the nursing staff prior to entering and visiting the room.
Meet the Team of Professionals Who Take Care of Your Child

A Long Term Care team assesses the needs of your child upon admission to Long Term Care and prepares a comprehensive care plan to meet their needs. Continual monitoring of your child's status assures that his or her care plan is adapted, thereby maximizing each child's potential. You and your child are important members of the team for planning care. After the initial comprehensive care plan we then meet quarterly at Patient Care Meetings (PCM) with you to discuss your child’s progress and future needs. You will be notified of the dates and times of the care plan meetings by the Patient Care Coordinator.

**Nurse Manager**
Mountainside: Imelda Shoola
908-301-5464
ishoola@childrens-specialized.org

Toms River: Jeanette Golden
732-797-3800
igolden@childrens-specialized.org

The Nurse Manager’s responsibilities are to ensure that hospital policies and procedures are carried out, that we have appropriate staff, and to generally make sure the Long Term Care Center runs smoothly and that the children’s needs are being met. She is available to help you and the staff with any questions or concerns that the person working directly with your child was not able to answer.

**Nurse Practitioner**
Mountainside: (Mon-Fri) Grace Page APN
908-301-5417
gpage@childrens-specialized.org

Toms River: (Mon-Thur) Christine SanPietro, APN
732-797-3835
csanpietro@childrens-specialized.org

Lauren Blann: (Friday)
732-797-3829
lblann@childrens-specialized.org

The Nurse Practitioner responsibilities are to perform the initial medical assessment, monitor progress, prescribe and supervise therapy, and meet regularly with the family.

A Nurse Practitioner or physician is on call 24 hours a day, 7 days a week.
Physicians
Dr. Colin O’Reilly – Medical Director for Long Term Care services
The Physicians responsibilities are to work closely with the Nurse Practitioner in the ongoing care of your child. The physicians do not have scheduled days on the floor but can be reached by the Nurse Practitioner as needed. The Physician with the Medical Director’s role is responsible for the quality of medical care throughout the center. A Family Nurse Practitioner or physician is on call 24 hours a day, 7 days a week.

Registered Nurses (RN) and Licensed Practical Nurse (LPN)
The registered nurse responsibilities are the coordination and planning of nursing care. They work with the LPN’s and Certified Nurse Assistants to evaluate each child's condition, to plan and implement nursing care, and to discuss current needs. A Registered Nurse is on duty at all times (24 hours a day). The nursing staff is responsible for providing direct care such as giving medications and specialized treatments as well as the physical care for your child’s daily needs. Please feel free to speak to the nurse concerning any questions or concerns you /your child may have.

Certified Nursing Assistants (CNA)
The Certified Nursing Assistant responsibilities are to work hand in hand with the nurses and therapists to make sure that your child’s daily needs are met. They take care of daily grooming and dressing needs and make sure that your child is comfortable and happy. Daily care routines and bath schedules are set up for each child.

Patient Care Coordinator-PCC
Mountainside: Toms River:
Evelyn Lozada-Sipe Maura Hines
908-301-5591 732-797-3833
ELOzada-Sipe@childrens-specialized.org mhines@childrens-specialized.org

A Patient Care Coordinator (previously known as Social Worker) will be available to support and assist you/your child and will maintain close contact with you. She can help you get answers to questions, find special resources for your child’s needs, inform you of special meetings and events and in general help you navigate the many journeys you will make in caring for your child.

Rehabilitation Technology
The Rehabilitation Technology department’s responsibility is to provide children with the proper seating and positioning devices, and mobility-access equipment such as wheelchairs, to enable children to interact with their environment.

The staff can provide children with access to the latest technology in orthodics and prosthetics.

Rev.12/17
Respiratory Care (limited services in our Toms River Center)
The Respiratory department is made up of some of the finest respiratory therapists in the state of New Jersey. Their role is to deliver breathing medications and therapies that support and maintain adequate ventilation, oxygenation and overall health. The respiratory therapists are hands-on at the bedside demonstrating the life-sustaining techniques ordered by our medical staff to improve your child’s ability to breathe. Our respiratory therapists will listen to breath sounds, evaluate air exchange, note the vitals signs, remove secretions and position the child to breathe at their best. Some of the advanced techniques our respiratory therapists perform are: tracheostomy removal and insertion, weaning from mechanical ventilation and on-site lab for blood gases, glucose, chemistry and keto levels. During extreme emergencies, our respiratory therapists will be right there to provide breathing and circulatory support including CPR. Our department staffs respiratory therapists on the unit around the clock, everyday and every night.

When it comes to learning the care of your child with a tracheostomy and/or with mechanical ventilation, our staff provides direct training and care techniques to allow greater opportunities to visit outside the facility to your home, special events and overnight stays. We are here to support you and your child.

Psychotherapist/Psychologist
The psychotherapist provides counseling services to your child and your family. These services are arranged for on referral by the care team.

Nutritionist Department
A comprehensive nutritional assessment is conducted to address the nutritional needs of your child. A dietary representative is part of the interdisciplinary team and attends care plan meetings every 3 months.

(Regarding Kosher Meals)
Children’s Specialized Hospital, Long Term Care, does not keep a kosher kitchen for food preparation and handling and only assumes responsibility for heating and serving frozen kosher meals, intact (in other words, in the packing in which they are delivered and with disposable plates and utensils). We do not accept responsibility for any other items placed on the food service tray or table. Children and families assume the responsibility for assuring that tray and table items meet their religious standards.
Pharmacist
The pharmacist dispenses and monitors all medication prescribed for the child. The hospital pharmacist is an integral member of the health care team. The pharmacist, physician and nurse work together to meet your child’s medication needs. In addition, all Long Term Care facilities also have a consultant pharmacist who audits all medications, interactions, etc and acts as a secondary check on all medication interactions, levels and uses.

Spiritual Needs/Chaplain
Mountainside:  
Rev. Ann Shamy  
908-233-3720 X 5060  
ashamy@childrens-specialized.org

Toms River  
Rev. Cherryl Baker  
732-797-3801  
cbaker@childrens-specialized.org

Please feel free to invite your clergy to visit your child. We would be happy to contact the clergy who visit our hospital on an on-call basis, should you wish them to meet with you and/or your child. Please speak to your nurse or other staff about any support you or your child have for meeting your spiritual needs. In addition, our Chaplain will see your child when they visit the center and provide spiritual direction at that time. If you have special requests for your child you can make them known to the chaplain. The chaplain is also a presence for the family for support and counseling.

Family Faculty
Mountainside:  
Linda Wadell  
908-301-5534 x5346  
jpearsall@childrens-specialized.org

Toms River:  
Jessica krill  
732-914-1100 X3716  
jkrill@childrens-specialized.org

Family Faculty will provide peer-to-peer support to assist families with transition and adjustment to the Long Term Care center. Family Faculty also works with the staff to ensure that family and child needs are met and assists with many of the family programs and activities. Family Faculty is a family member who currently has or previously had a child who received services from Children’s Specialized Hospital.
Manager/Supervisor of Long Term Care Therapy Services
Mountainside: Rayna Correia, CTRS
908-233-3720 x5362 RCorreia@childrens-specialized.org
Toms River: Caroline Romond, CTRS
732-914-1100 X3716 cromond@childrens-specialized.org

The Long Term Care Therapy Service is designed to (1) maintain and support function when possible or (2) reduce, slow and minimize loss of function in cases of debilitating progressive diseases when possible or (3) increase or support function when new abilities or developmental progress are demonstrated. Full assessments to determine therapeutic needs are provided at the time of admission, as per plan of care, annually, and upon observation of major change in status.

The Long Term Care Therapy team is: Physical therapist, Occupational Therapist, Speech Therapist, Restorative Nursing Assistant, Recreational Therapist and Child Life Specialist.

Physical Therapist
The Physical therapist responsibilities are to work with each child to maintain or improve range of motion, and promote independent functional mobility through exercises, both active and passive, functional positioning, and through the use of braces and positioning equipment. The Physical Therapist has a Bachelor's, Master's or Doctoral degree in PT and is licensed by the State Board of Physical Therapy.

Occupational Therapist
The Occupational Therapist responsibilities are to focus on activities that improve functions of the hands, arms, and upper body, as well as eye-hand coordination and various motor skills that help contribute to the child's physical and emotional independence. The Occupational Therapist has a Master’s degree in Occupational Therapy. The National Board certifies them for Certification in Occupational Therapy and Licensed by the Occupational Therapy Advisory Council

Speech Therapist
The Speech Therapist responsibilities are to work with each child to assess their ability to eat, swallow and communicate. If the child is able to eat by mouth, the speech therapist will help to determine the best food/texture for their diet. The speech therapist also accesses the child’s ability to communicate both verbally and/or through alternate means of communication which includes use of switches, picture boards, etc.
The Speech Therapist has a Bachelor’s or Masters in speech pathology. They have a Certificate of Clinical Competence as well as a state license with New Jersey through the Speech Language and Audiology Licensing Board.
Recreational Therapist
Recreational Therapists responsibilities are to utilize play, recreation, and leisure activities to improve the physical, cognitive, sensory and social/emotional abilities of infants, toddlers, children and adolescents. The primary purpose of their treatment is to identify, improve and/or enhance the functional abilities and independence of the children through leisure and play skills/techniques. We also focus on engaging the children through play and social opportunities in evening recreation activities, special events, open recreation play times, pet therapy programming and music therapy. There are many volunteers who work with the recreational therapist to provide family activities, community out trips, patient pals and cuddler programs.

The Recreational Therapists at Children’s Specialized Hospital are prepared at the bachelor or master’s level in Therapeutic Recreation. They are certified by the National Council for Therapeutic Recreation Certification and are an integral part of the Long Term Care team.

Child Life Specialist
Child Life Specialists’ responsibilities are to use age/cognitively appropriate activities to provide support, distraction, pain management, and coping education for medical and therapy procedures. They assist children and adolescents with adjustment to hospitalization and injury/diagnosis by promoting coping skills and expression of feelings. They are also available to work with families to facilitate sibling education and coping.
Child Life Specialists are prepared at the bachelor’s and master’s levels in Child Life, Child Life Development and other related fields. They are certified by the Child Life Council and are an integral part of the Long Term Care team.

Therapy Assistant
Therapy assistants work with the therapy team to provide additional one on one supervision and/or additional engagement opportunities for the children.

The Restorative Nursing Assistant
The Restorative Nursing Assistant responsibilities are to act as a liaison between the nursing department and the therapy teams. The Restorative Nursing Assistant assists the nursing staff to carry out a restorative plan set forth by the therapy team.
Overview of Long Term Care Therapy

The Long-Term Care Therapy Program is designed with these Goals:

- Maintain and support function
- When possible:
  - Reduce, slow and minimize loss of function in cases of debilitating progressive diseases or
  - Increase or support function when new abilities or developmental progress are demonstrated.

An Individualized Care Plan is designed for your child

A team of licensed therapists conducts a full assessment of your child at the time of admission and then develops an Individualized Care Plan. After this initial assessment, we continually work to achieve your child’s goals by observing your child and identifying major changes in status that may necessitate a revised Individualized Care Plan. We will also reevaluate your child annually and make changes as necessary to their Individualized Care Plan.

Licensed therapy professionals oversee each Individualized Care Plan

Licensed therapy professionals (Physical Therapy, Occupational Therapy, Speech Therapy, Recreational Therapy, and/or Child Life) oversee Restorative Nursing Assistants and Group Therapeutic sessions. Also, if identified in your child’s Care Plan, Individual Therapeutic sessions involve designated licensed clinician(s) consisting of Restorative Nursing Assistant, Rehabilitation Technology, Physical Therapy, Occupational Therapy, Speech Therapy, Recreational Therapy, and/or Child Life)

Individualized Care Plan communication to Families

If you have any questions please ask the Supervisor of Long Term Care Therapy services or the Patient Care Coordinator. We are always open to discussing your child’s needs. A printed copy of your child’s Care Plan is available to you. The initial plan of care for admission is available to you within 48 hours and a comprehensive care plan developed after your child’s complete evaluation has been conducted. Updated plans of care are done every 3 months or with significant changes and available to you at your child’s patient care meeting or as requested.
Traditional vs. Non-Traditional Therapy

Your child’s therapy goes beyond the traditional therapy mentioned above (Physical Therapy, Occupational Therapy, Speech Therapy, Recreational Therapy, and/or Child Life) in the Long Term Care center. We know through years of experience that your child benefits from all the therapies we can provide, whether they are traditional or non-traditional.

Non-traditional therapy involves engaging all the five senses in daily setting:

- Touch
- Smell
- Sight
- Taste
- Hearing

A child’s first and most important sense is that of touch. It is the first sense your child developed in the womb. Babies need it to survive and grow, and the need for touch remains with them throughout their lives. In the 1940’s Dr. Fritz Talbot discovered that in a children’s clinic babies that were being held, touched and mothered were thriving when all other medical possibilities had been exhausted. Here in the Long Term Care Center your child experiences the sense of touch daily through:

- Daily grooming- hair brushed, mouth cleaned, clothes changed, nose wiped
- Talking with your child during the day
- Diaper changes
- Bathing
- Receiving their medications
- Receiving their food (by mouth or feeding tube)
- Getting out and into their bed
- Getting out and into their chair
- Being put in a swing or playpen
- Being out in the main areas with their peers/staff
- Riding the bus (School age children)
- Being strolled in their wheelchair
- Kiss or stroke on the head, pat on the back, stroke of the hand
Along with these daily experiences, there are many other activities your child may be a part of that involve touch and other 4 senses:

**Sensory Rooms/Spaces – These areas are** designed to create a relaxing sensory experience for your children. The children get out of their chairs and actively explore their environment. The room has bubble tubes, special mats, seating and lighting. (all five senses)

**Pet Therapy- Therapy** Pets/Visiting Pets come to the Long Term Care center periodically. Stroking an animal’s fur (assisted or unassisted) is a wonderful stress reliever. The children love their visits with the animals. (Senses: touch, smell, hearing, sight)

**Cuddlers -** Volunteers come regularly throughout the week to hold and rock, read, play/interact, and stroll your child throughout the unit. (Senses: touch, smell, hearing, sight)

**Sensory Groups-** Multidisciplinary groups are run by various combinations of Occupational Therapy, Physical Therapy, Speech Therapy, Recreational Therapy and, Child Life. The children participate in different types of activities that stimulate all their senses. (All five senses)

**Open Recreation -** Throughout the day, when the Therapy Suite is not being used for scheduled therapies, the children come to participate in play activities with their peers, volunteers, and staff. Open recreation time includes playtime with staff and volunteers, computer time, video games, arts & crafts, movies, board games, and sensory based activities. (Senses: touch, smell, hearing, sight)

**Evening and Weekend Recreation -** Recreational activities are scheduled for the children throughout the week. Children participate in all kinds of activities, such as arts & crafts, gross motor play, sensory play, social activities, special events. (Senses: touch, smell, hearing, sight)

**Volunteers-** Group volunteers (schools, companies, town organizations and religious organizations) as well as Children’s Specialized Hospital individual volunteers come daily to play, interact, and engage your child during afterschool hours, evening recreation programs and during open recreation. They are individual and group based volunteers. (Senses: touch, smell, hearing, sight)

**Patient Pals-** 1:1 volunteers that come to play, engage, and interact with your child during afterschool hours. They also, help your child with homework. (Senses: touch, smell, hearing, sight)
Out of the Building Trips- Periodically some of the children take trips into the community (All 5 senses)

Switch Toys-A switch adapted toy is a toy that has been modified so that the children can press a switch and activate the toy. Adaptive toys are used to improve a skill or reach a developmental goal. Toys can be adapted to involve any of the three senses (Senses: sight, touch, and hearing)

Interactive computer/Video Games - There are computers and video games available for the children to use in the dayroom. (Senses: sight, touch, hearing)

Switch Computer Programs – Computer programs are used that are easy for the children to interact with the computer. (Senses: sight, touch, hearing)

Television-Televisions are available throughout the center. The programming watched is always suitable for children. Children enjoy the sounds and visuals in the kid programming. (Senses: sight, hearing)

Music Therapy- Music Therapy is used with the children since it’s benefits are many. It helps reduce stress and anxiety and studies have shown that it is beneficial to respiratory rate and improves mood while enhancing quality of life. (Sense: hearing, touch)

Age/cognitively appropriate toys and Cause /effect light up toys- Toys that stimulate the senses are placed bedside or can be placed on the children’s lap trays to encourage play and interaction when sitting in their chairs. (Sense: Sight, touch, hearing)

Special Events - There are many Special Events scheduled throughout the year such as Holiday Parties, Petting Zoo, musicians, Beach Party and Family Photo day

Family Day Weekend Special Events- There are Family Day Events scheduled once or twice a quarter for families to gather together to enjoy a movie, snacks and the company of other families in the Long Term Care center.

Church Services- one Sunday a month. -There is a scheduled Church service one Sunday a month. If you would like your child to participate please let the Patient Care Coordinator know.

Visits with Family- your child always enjoys a visit from their families
How to Obtain Information about your Child

Everyone here at the Long Term Care center is ready to help answer any questions you may have about your child. Here are some common inquiries and how to obtain the information.

Information about your child’s current Nurse and CNA (Certified Nursing Assistant)
You can find this information by:

- Calling the Long Term Care Center
- Checking the Nurse and CNA assignment board located across from the Nurse’s station
- Asking any nurse or CNA to check who is your child’s nurse.

Information about your child’s progress
We are open to discuss your child’s progress at any time. There are many ways to check on the progress of your child, here are several ways:

- Ask your child’s nurse, the Nurse Manager, Nurse Practitioner or Therapy Supervisor how your child is doing at any time.
- Schedule a meeting with the Nurse Manager, Nurse Practitioner or Therapy Supervisor.
- Attend the Patient Care Meeting (PCM)
The Patient Care Meeting is a chance for you to meet and partner with your child’s team while discussing your child’s progress. You will meet on a quarterly basis with selected team members including the Nurse Practitioner, Nurse Manager, Patient Care Coordinator and Therapist. The Patient Care Coordinator (PCC) will let you know in advance when the meeting will be held. At this meeting we will discuss your child’s vitals, quarterly health updates, progress towards goals set by therapy and any matters that are important to you in the care of your child.

Information on access to your child’s records through the Parent Portal
As a parent/guardian you can access your child’s medical record on line to review physician and therapy reports, medications, vitals, allergies and history. To gain access these services, you must speak with a registration representative while at the Center to receive a “patient code”. This will allow you to access your child’s record through the internet at:

My.childrens-specialized.org
**NJ State Requirements for Long Term Care: Hours of Care Required**

Children’s Specialized Hospital or any Long Term Care center in New Jersey is required to provide the following hours of care for each child per day. The minimum hours required is 2.5 hours per day for Basic Care. If a child has other needs, such as oxygen therapy, extra time is added.

<table>
<thead>
<tr>
<th>NJ State Care Requirements</th>
<th>Required Hours per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Care</td>
<td>2.5 (2 hours &amp; 30 min)</td>
</tr>
<tr>
<td>Wound Care</td>
<td>0.75 (45 min)</td>
</tr>
<tr>
<td>Oxygen Therapy</td>
<td>0.75 (45 min)</td>
</tr>
<tr>
<td>Tracheotomy or Ventilator</td>
<td>1.25 (1 hour &amp; 15 min)</td>
</tr>
<tr>
<td>Gastric Feeding Tube, or Nasogastric Feeding Tube, or Jejunostomy Feeding Tube</td>
<td>1.0</td>
</tr>
<tr>
<td>Neuro/Ortho</td>
<td>1.5 (1 hour &amp; 30 min)</td>
</tr>
</tbody>
</table>

**Our Special Long Term Care center Manners and Privacy**

**Long Term Care Manners**

To provide each child with dignified and tender loving care we ask that every family visiting the Long Term Care center observe the following manners. These manners ensure that we are considerate of the rights of the children, families and staff at all times.

- Please speak softly to your child.
- Please speak in a courteous manner at all times when addressing the staff.
- Please close the curtain when your child is changing.
- Please respect the privacy of others when the curtain is closed.
- Please be respectful of the space around your child’s bed. Use the storage areas.
- Please use common visiting spaces when there are more than four visitors here to see your child.
- Please keep the volume of music and televisions just for your child to hear.
- Please, no touching, feeding, bathing, or dressing of other children.
- Please respect everyone’s privacy.
- If you think a child needs assistance, please contact nursing.
Tips from families whose children live or lived in our Centers:

- Ask questions about your child’s care - any question.
- Think about how you understand medical information and let us know what your best way to learn is.
- It’s difficult to know your state of mind right now but as a family member you might want to remember all of the details. It’s OK to write them down.
- Don’t be afraid to tell staff about your child, even if they look busy.
- Taking pictures to help capture moments along the way. You are only permitted to take pictures of your own child.
- If you are having trouble keeping track of what’s going on, keep a planner/log.
- Let yourself take a break when you feel the need.
- Your child loves to get hugs and kisses from you and your family. Come and share time with them. Weekends are a great time to visit your child.
- Think Positive
Your Child’s Safety and Infection Control are Important to Us

Safety

- For the safety of your child, side rails must be kept in the “up” position when you are not directly at the bedside.
- For the safety of our children and for infection control we emphasize that family and visitors are not permitted to hold or care for other children on the unit.
- For the safety of our children, siblings must be supervised at all times and are not allowed to enter other children’s rooms.
- If your child walks, they are required to wear some kind of shoe.
- All children must wear seatbelts when in wheelchairs.
- Helmets are used for protection and may be required based on the individual child’s needs.
- Latex balloons are not allowed as they are a choking hazard and/or can cause an allergic reaction-Mylar balloons are fine.
- We are required to do testing of the fire bells and/or conduct other drills routinely. You will be instructed on what to do.

Safe Patient Handling Program

We have a safe patient handling program. The purpose is to achieve an environment in which safe lifting and movement of children is practiced as part of an overall culture of safety.

- Use of mechanical lifting devices greatly reduces back injuries to healthcare workers and also promotes child safety.
- Manual lifting and moving of children is to be minimized as much as possible except when working toward therapy goals.
- Talk to your child’s nurse or therapist if you have any questions regarding the safe handling of your child or our policy on Safe Patient Handling Program.

(State of NJ mandatory “Safe Patient Handling Act effective 1-1-2011)
Infection Control

We use standard precautions to prevent the spread of infection. Standard precautions means taking care not to have direct contact (touch) with blood or body fluids from any child. The most important way to stop the spread of infection is by good hand washing techniques.

Please use the following guidelines:

- Wash hands before and after visiting.
- Wet hands and wrists and clean with warm water.
- Use soap and lather in hands for 20 seconds.
- Dry hands with a clean paper towel and throw away.
- Use a new paper towel to turn the water off.

If hands are not visibly dirty, alcohol gel may be used to kill germs of the hands. Gel dispensers are available in many locations throughout the hospital.

If your child is on infection precautions there will be a sign at the door and at the bedside. Please check with the nurse to find out exactly what precautions are needed. Also, if there is a stop sign on your child’s door please check with nurse before entering the room.
Your Child’s Clothing and Personal Belongings

Children’s Clothing
- Please label your child’s clothing and belongings with his/her name.
- The children are dressed in their own clothing. Loose fitting garments are preferred (clothes that are easy to put on and take off).
- Your child should have enough clothing to accommodate up to 3 times changes of clothing daily as well as pajamas for the evening.
- We will place your child’s soiled clothes in a laundry bag kept at the bedside for your convenience. You may wash your child’s clothes either at home or use the shared washer and dryer located in the Long Term Care center. You may use the detergent that we have available. Staff will do the laundry routinely if you choose not to launder your child’s clothing.
- Please clean out clothes - bring home clothing that no longer fits your child, as well as clothing that may not be seasonally appropriate

Personal Belongings
- Please do not bring stuffed animals since they are very difficult to clean and gather germs and viruses that can spread to your child and other children in the room.
- Please do not put valuable items in your child’s bedroom as this is an open floor and we are not responsible for lost or stolen items.
- Please feel free to personalize your child’s space with pictures and decorations.
- Please be careful of your personal belongings (especially handbags, iPhones, iPods, and computers) when you are visiting your child, as the hospital cannot be responsible for lost or stolen items.
- All electrical items from home for your child to use (radios, computer and cell phone chargers) MUST be inspected by the engineering department. Please take these items to a staff member and they will be happy to help you.
Other Helpful Information about the Long Term Care Center

Parent Bulletin Boards
We have multiple bulletin boards throughout the center to communicate with you. You can use these boards to check to see who is taking care of your child, updates on policies and regulations or just general information and bulletins about upcoming events. In addition, copies of materials are available for you to take with you. Please look for these boards as you walk through the centers to become familiar with where each type of information is posted and shared.

Care Pages.com
CarePages.com is a free; Internet based service that enables parent’s to easily share information with family and friends about their child’s progress while they are here at Children’s Specialized Hospital or at home. It is a safe, easy to use, password protected and unique website for each family. Through this personalized website, parent’s can relate stories, post photos and update family and friends instantly and once. Parent’s now have a venue where everybody can keep updated on a child’s progress just by signing in to the personalized website, and parent’s only have to enter the information once. In turn, family and friends can send messages of love and encouragement. You can visit www.Carepages.com to easily set up your website today. They provide very easy step-by-step instructions.

Confidentiality
In order to protect each child’s privacy and confidentiality, staff is not permitted to discuss any aspect of a child’s care with anyone other than his/her immediate family/legal guardian.
  - Families may not photograph or videotape any other child or child other than your own.
  - We encourage families to seek support from one another, but please do not ask staff about other children.

Immunizations
Please bring in a copy of your child’s immunizations record and give it to the nursing staff. During your stay you may be contacted for consent when and if further immunizations are needed. Information about all immunizations is available and may be obtained by asking your nurse.
Transfers/Bed Holds
If your child should need to be transferred from Children’s Specialized Hospital Long Term Care center to another facility for urgent medical needs, surgery or therapeutic leave, Medicaid has established a 10-day bed hold regulation. Please note that this policy is not unique to Children’s Specialized Hospital Long Term Care center. Our first priority is always to bring your child back to Children’s Specialized Hospital. However, the State of New Jersey Medicaid program licenses the beds at Children’s Specialized Hospital and due to this we are obligated by law to follow the Medicaid regulations.

Leave of Absence/ Overnight Visits Home – referred to as FTVs (Function Trial Visits or FSAs – Functional Skills Assessment)
The Patient Care Coordinator will discuss with you the policy on overnight visits for your child. The state limits the number of overnight visits per year to 24.

When your child reaches School Age
All children ages 3-21 are entitled to educational services. Your Patient Care Coordinator (PCC) will assist you in working with your local school district in determining the least restrictive educational environment for your child and facilitating placement there. As the parent/guardian, you are the legal representative for your child to their school district.

Food & Drink
Meals, beverages and snacks are available to visitors in the cafeteria in Mountainside. The cafeteria is open to families and visitors. In our Toms River center vending machines with snacks and drinks are located in the outpatient area of the building. Please speak with the nursing team for guidance in where to best have food when visiting with your child.

Rest Rooms
All visitors are asked to use the rest rooms in the hallways. All bathroom facilities located in the children’s rooms are solely for the child’s use. Please check with hospital staff as to the location of the restroom(s).

Phone
The use of cell phones is allowed on the floor as long as it does not negatively impact the care or comfort of the children. For your convenience and privacy, there are phones available for your use. Please check with your nurse or at the nursing stations for their location and usage instructions.
Family Guidelines for visiting other places in the Hospital outside of the Long Term Care Center

We know that families enjoy visiting other areas of the hospital and getting outside when your child’s condition permits. If the Nurse Practitioner permits your child to leave the Long Term Care Center, the following steps need to be taken:

- Parents must complete required training on your child’s care.
- If your child’s condition changes, return to the floor and tell your nurse.
- Parents should let the Nursing Staff know they are leaving the center.
- Upon returning to the Long Term Care center, be sure to let the staff know you are back.
- Children and families are permitted in all the general areas such as the courtyards, cafeteria, and the playground. (See next page for details for each center)
Places to visit with your child in and around the Long Term Care Centers

Taylor’s Garden - Mountainside
Taylor’s Garden is located right outside the Long Term Care doors that are located in the middle of the Long Term Care Floor (the west end of the floor). You are welcome to visit with your family and child, if your child has Doctor or Pediatric Nurse Practitioner permits your child to leave the Long Term Care floor. Taylor’s Garden is a courtyard, with plenty of shade, flowers, tables and chairs and a fountain. It is a peaceful place to just enjoy your child and family.

Courtyard – Toms River
The courtyard is located right outside of the dining/play room and has doors at each end for entry and exit. There are tables and chairs, a shade awning and a pleasant setting to enjoy outside time with your child and family.

Playground
The Playground in Mountainside is located on the same floor as the Long Term Care Center. The playground has wheelchair accessible equipment that is bright, fun and interactive. It’s a wonderful place to go with your child and family. The Playground in Toms River is located in a courtyard in the center of the building and has access doors by the vending machines and from the Center. As these doors may have alarms please speak with security and/or nursing and therapy team members to insure they are open for both entering the courtyard and returning inside.

Family Lounge Areas
In Mountainside: There are two family lounge areas located on each end of the center. These rooms are designed for families to visit with their children, use for special events, watch TV, and socialize with other Long Term Care families. Food and drinks are permitted in these areas.
In Toms River: There is a family visit room just outside the inner doors to the Center and has comfortable chairs, a table set up and TV for private visits with your child.

Therapy and Day Rooms
The Therapy and Day Rooms are located in the therapy hallways of each center. They are used for therapy, group activities, (alternative therapies), open and evening recreation. The therapy rooms have special ceiling lifts which will enable the bigger kids to be lifted out of their chairs and have opportunities to engage in activities. There are pods in the room for the infants to have opportunities to get out of their strollers/wheelchairs to freely explore and engage in their environment. This room is

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open for families to participate in activities with their children when there is a therapist present. This is a therapy interaction room and no food or drinks permitted.

Mountainside Trails
The Mountainside Trails are located behind the hospital. The trail is 9/10th mile long. The new trail surface is a track mix that is easy on the knees and joints. You are welcome to walk or stroll along the scenic trail.
Map of the Hospital
General information about Children’s Specialized Hospital

Smoking
Children’s Specialized Hospital is a smoke free institution. Smoking is not permitted by visitors and only by residents as per State and CMS guidelines. If a resident of age smokes, arrangement will be made with the individual center.

Guardianship
Before a Long Term Care resident reaches the age of eighteen (18), a determination needs to be made as to whether he or she will, at age 18, be able to act as his or her own guardian. A guardian is the person responsible for decisions concerning the resident’s medical, legal and financial affairs. If it is determined that the resident cannot act as such, a parent may choose to apply to become the court-appointed guardian, or have another adult appointed as guardian. Families are encouraged to discuss this issue with the resident’s physician and social worker two to three years prior to the resident’s eighteenth birthday, in order that any actions needed to appoint guardianship may be made by the family in a timely manner.

Ethics Committee/ Health Care Concerns
Concerns of an ethical nature may be given to the ethics committee. Concerns are made to the committee in writing with respect to the child’s rights and confidentiality. The purpose of the committee is to provide assistance to the child, family and doctor in regards to ethical decision making. This may include organ donation, treatment refusal, informed consent, and withdrawal or continuation of life support. This committee does not replace the relationship between the child, family and physician. The committee includes doctors, nurses, therapists, social worker, administrators, trustees, family representatives, clergy and legal representation. In compliance with the Patient Self-Determination Act, your Patient Care Coordinator/PCC will provide you with information. If the child is 18 years of age or older he/she will be informed.

Advanced Directives
Children’s Specialized Hospital will provide all mentally competent children 18 years and older a copy of the New Jersey Department of Health Document titled “Your Right to Make Health Care Decisions in New Jersey” and review it with you. A Do Not Resuscitate (DNR) or Do Not Hospitalize (DNH) advanced directive will be offered to families in the Long Term Care center.
Complaint Procedure
Professional members of the interdisciplinary team (physicians, nurses, therapists, and Patient Care Coordinator) are available to talk with children and families about any problems or questions that may be of concern to them. Members of hospital management will meet with the child, family or visitor to discuss unresolved complaints in an effort to arrive at a mutually satisfactory resolution. In addition, Parents have access to express their concerns to Long Term Care Administrator, the Vice President of Patient Care, and/or the Medical Director, when they feel their problem is urgent or unresolved. The Long Term Care Administrator is designated as the Grievance Officer. Access to the New Jersey Department of Health is: 1-800-792-9770

Child and Family Responsibilities:
- To provide accurate and complete information concerning his/her present complaints, past illnesses, hospitalizations, and other matters relating to his/her health.
- To make it known whether he/she clearly comprehends the course of his/her medical treatment and what is expected of him/her.
- To follow hospital policies and procedures.
- To contact their Patient Care Coordinator with any issues/concerns/complaints.
- To provide Patient Care Coordinator with all information needed to provide for child’s educational needs.
- When discharge planning is indicated, family is active participant.
Discharge Planning

Depending upon your child’s nursing care needs and clinical progress, the length of stay will vary for each child. Discharge could occur:

1. When the transfer or discharge is necessary to protect the Child's welfare;
2. When the Child's health has improved so that the Child no longer needs the services provided by the Facility, or when the child would be better served in a less restrictive environment;
3. Upon a determination that a Child’s behavior poses a danger to self and/or others, as determined in accordance with federal and/or state laws;
4. When the Child's account is more than fifteen days in arrears (unless the Child is eligible for Medicare or Medicaid);
5. If the Facility ceases to operate, or
6. Upon the Child’s 18th birthday. Continued stay beyond age 18 is at the sole discretion of the Facility, contingent upon the availability of alternative placements for Child; continuation of Child’s eligibility of third party payments, where applicable; continued authorization for the placement at Facility by a state agency; or the existence of a waiting list for a bed at the Facility for eligible children under age 18. In no case may the Child’s continued stay at the Facility extend beyond the Child’s 21st birthday.
Children's Specialized Hospital Vision, Mission and Values

Vision

A world where all children can reach their full potential.

Mission

The mission of Children's Specialized Hospital is to be the preeminent provider of specialized healthcare services for infants, children and young adults.

Values

Our trustees, employees and volunteers will embody our values in every interaction with children, their families, each other and all other stakeholders. Our values are:

Compassion: We provide a loving, caring family-centered environment for the children, their families, and each other. We advocate for children and their families.

Integrity: We are committed to organizational and financial accountability, transparency, respect for all, and ethical practices.

Excellence: We will be the best at our work and provide the highest quality family-centered care to our children, constantly striving to improve.

Innovation: We go above and beyond the norm and will be creative in providing care and solving problems.

Teamwork and Collaboration: We seek to collaborate and partner in all that we do. We are a team where every person is needed to provide the quality care for which we are known. We work together and communicate effectively.

Fun: We will provide a positive and friendly environment.
Patient Rights

Each resident shall be entitled to the following rights:

1. To retain the services of a physician or advanced practice nurse the resident chooses, at the resident's own expense or through a health care plan;

2. To have a physician or advanced practice nurse explain to the resident, in language that the resident understands, his or her complete medical condition, the recommended treatment, and the expected results of the treatment, except when the physician deems it medically inadvisable to give such information to the resident and records the reason for such decision in the resident's medical record; and provides an explanation to his or her next of kin or guardian;

3. To participate, to the fullest extent that the resident is able, in planning his or her own medical treatment and care;

4. To refuse medication and treatment after the resident has been informed, in language that the resident understands, of the possible consequences of this decision. The resident may also refuse to participate in experimental research, including the investigations of new drugs and medical devices. The resident shall be included in experimental research only when he or she gives informed, written consent to such participation;

5. To be free from physical and mental abuse and/or neglect;

6. To be free from chemical and physical restraints, unless they are authorized by a physician or advanced practice nurse for a limited period of time to protect the resident or others from injury. Under no circumstances shall the resident be confined in a locked room or restrained for punishment, for the convenience of the nursing home staff, or with the use of excessive drug dosages;

7. To manage his or her own finances or to have that responsibility delegated to a family member, an assigned guardian, the nursing home administrator, or some other individual with power of attorney. The resident's authorization must be in writing, and must be witnessed in writing;

8. To receive a written statement or admission agreement describing the services provided by the nursing home and the related charges. Such statement or admission agreement must be in compliance with all applicable State and Federal laws. This statement or agreement must also include the nursing home's policies for payment of fees, deposits, and refunds. The resident shall receive this statement or agreement prior to or at the time of admission, and afterward whenever there are any changes;
9. To receive a quarterly written account of all resident's funds and itemized property that are deposited with the facility for the resident's use and safekeeping and of all financial transactions with the resident, next of kin, or guardian. This record shall also show the amount of property in the account at the beginning and end of the accounting period, as well as a list of all deposits and withdrawals, substantiated by receipts given to the resident or his or her guardian;

10. To have daily access during specified hours to the money and property that the resident has deposited with the nursing home. The resident also may delegate, in writing, this right of access to his or her representative;

11. To live in safe, decent, and clean conditions in a nursing home that does not admit more residents than it can safely accommodate while providing adequate nursing care;

12. To be treated with courtesy, consideration, and respect for the resident's dignity and individuality;

13. To receive notice of an intended transfer from one room to another within the facility or a change in roommate, including a right to an informal hearing with the administrator prior to the transfer as well as a written statement of the reasons for such transfer. The nursing home shall not move the resident to a different bed or room in the facility if the relocation is arbitrary and capricious. A transfer would not be considered arbitrary and capricious if a facility can document a clinical necessity for relocating the resident, such as a need for isolation or to address behavior management problems, or there is a hardship to an applicant for admission through a delay caused by inefficient distribution of beds by gender;

14. To wear his or her own clothes, unless this would be unsafe or impractical. All clothes provided by the nursing home shall fit in a way that is not demeaning to the resident;

15. To keep and use his or her personal property, unless this would be unsafe, impractical, or an infringement on the rights of other residents. The nursing home shall take precautions to ensure that the resident's personal possessions are secure from theft, loss, and misplacement;

16. To have physical privacy. The resident shall be allowed, for example, to maintain the privacy of his or her body during medical treatment and personal hygiene activities, such as bathing and using the toilet, unless the resident needs assistance for his or her own safety;
17. To have reasonable opportunities for private and intimate physical and social interaction with other people, including arrangements for privacy when the resident's spouse visits. If the resident and his or her spouse are both residents of the same nursing home, they shall be given the opportunity to share a room, unless this is medically inadvisable, as documented in their records by a physician or advanced practice nurse;

18. To confidential treatment of information about the resident. Information in the resident's records shall not be released to anyone outside the nursing home without the resident's approval, unless the resident transfers to another health care facility, or unless the release of the information is required by law, a third-party payment contract, or the New Jersey State Department of Health and Senior Services;

19. To receive and send mail in unopened envelopes, unless the resident requests otherwise. The resident also has a right to request and receive assistance in reading and writing correspondence unless it is medically contraindicated, and documented in the record by a physician or advanced practice nurse;

20. To have unaccompanied access to a telephone at a reasonable hour to conduct private conversations, and, if technically feasible, to have a private telephone in his or her living quarters at the resident's own expense;

21. To stay out of bed as long as the resident desires and to be awakened for routine daily care no more than two hours before breakfast is served, unless a physician recommends otherwise and specifies the reasons in the resident's medical record;

22. To receive assistance in awakening, getting dressed, and participating in the facility's activities, unless a physician or advanced practice nurse specifies reasons in the resident's medical record;

23. To meet with any visitors of the resident's choice between 8:00 A.M. and 8:00 P.M. daily. If the resident is critically ill, he or she may receive visits at any time from next of kin or a guardian, unless a physician or advanced practice nurse documents that this would be harmful to the resident's health;

24. To take part in nursing home activities, and to meet with and participate in the activities of any social, religious, and community groups, as long as these activities do not disrupt the lives of other residents;

25. To leave the nursing home during the day with the approval of a physician or advanced practice nurse and with the resident's whereabouts noted on a sign-out record. Arrangements may also be made with the nursing home for an absence overnight or longer;
26. To refuse to perform services for the nursing home;

27. To request visits at any time by representatives of the religion of the resident's choice and, upon the resident's request, to attend outside religious services at his or her own expense. No religious beliefs or practices shall be imposed on any resident;

28. To participate in meals, recreation, and social activities without being subjected to discrimination based on age, race, religion, sex, nationality, or disability. The resident's participation may be restricted or prohibited only upon the written recommendation of his or her physician or advanced practice nurse;

29. To organize and participate in a resident council that presents residents' concerns to the administrator of the facility. A resident's family has the right to meet in the facility with the families of other residents in the facility;

30. To discharge himself or herself from the nursing home by presenting a release signed by the resident. If the resident is an adjudicated mental incompetent, the release must be signed by his or her next of kin or guardian;

31. To be transferred or discharged only for one or more of the following reasons, with the reason for the transfer or discharge recorded in the resident's medical record:

   i. In an emergency, with notification of the resident's physician or advanced practice nurse and next of kin or guardian;

   ii. For medical reasons or to protect the resident's welfare or the welfare of others;

   iii. To comply with clearly expressed and documented resident choice, or in conformance with the New Jersey Advance Directives for Health Care Act, as specified in N.J.A.C. 8:39-9.6(d); or

   iv. For nonpayment of fees, in situations not prohibited by law;

32. To receive written notice at least 30 days in advance when the nursing home requests the resident's transfer or discharge, except in an emergency. Written notice shall include the name, address, and telephone number of the New Jersey Office of the Ombudsman for the Institutionalized Elderly, and shall also be provided to the resident's next of kin or guardian 30 days in advance;
33. To be given a written statement of all resident rights as well as any additional regulations established by the nursing home involving resident rights and responsibilities. The nursing home shall require each resident or his or her guardian to sign a copy of this document. In addition, a copy shall be posted in a conspicuous, public place in the nursing home. Copies shall also be given to the resident’s next of kin and distributed to staff members. The nursing home is responsible for developing and implementing policies to protect resident rights;

34. To retain and exercise all the constitutional, civil, and legal rights to which the resident is entitled by law. The nursing home shall encourage and help each resident to exercise these rights; and

35. To voice complaints without being threatened or punished. Each resident is entitled to complain and present his or her grievances to the nursing home administrator and staff, to government agencies, and to anyone else without fear of interference, discharge, or reprisal. The nursing home shall provide each resident and his or her next of kin or guardian with the names, addresses, and telephone numbers of the government agencies to which a resident can complain and ask questions, including the Department and the Office of the Ombudsman for the Institutionalized Elderly. These names, addresses, and telephone numbers shall also be posted in a conspicuous place near every public telephone and on all public bulletin boards in the nursing home.

(b) Each resident, resident's next of kin, and resident's guardian shall be informed of the resident rights enumerated in this subchapter, and each shall be explained to him or her. None of these rights shall be abridged or violated by the facility or any of its staff.

Please report complaints and concerns to:

Nurse Manager: Imelda Shoola for our Mountainside Center
908 301-5464 ishoola@childrens-specialized.org
Jeanette Golden for our Toms River Center
732 797-3800 jgolden@childrens-specialized.org

Administrator/Grievance Official: Elaine Mustacchio for both Centers
908 301-5407 emustacchio@childrens-specialized.org

State Department of Health Complaint Hotline: 1-800-792-9770

State Department of Children and Families Hotline: 1-877-652-2873
Frequently Asked Questions

Where is the laundry room?
The laundry rooms are located in the center hallways in the Mountainside Long Term Care center. The laundry room in the Toms River Center is located across from the dining/day room.

Can I wash my child’s clothing?
Yes, you can wash your child’s clothing here or at home, but if you choose not to wash your child’s clothing, the Long Term Care staff will wash them.

Where is the room my child is bathed in?
In Mountainside the bathing rooms are located in the middle of the long hall way closest to the back of the hospital in the Long Term Care center and in the cross hall near the entrance area
In the Toms River Center the bathing room is located at the end of the therapy hallway.

Can I help bathe my child?
Yes, you are always welcome to help bathe your child. Your child’s certified nursing assistant (cna) will be happy to assist you in bathing your child. You can check with your child’s cna for the specific days your child is bathed so you can be present during their bathing time.

How often is my child bathed?
Your child is bathed 2 times per week, but each morning when your child starts their day they are cleaned, their teeth are brushed and hair is combed.

How often is my child’s room cleaned?
Your child’s room is cleaned daily.

How often are my child’s linens changed?
Your child’s linens are changed weekly and as needed.

How often is my child’s wheelchair fully cleaned?
A full cleaning of the wheelchair is completed monthly but any minor cleaning is done daily.

How often is my child positioned?
Your child is positioned every 2 hours to help prevent the development of pressure ulcers.
How often are my child’s vital signs (temperature, taken?)
Vital signs, (temperature, pulse rate, blood pressure and respiratory rate) are taken monthly to access the basic body functions. If your child becomes sick the vital signs are taken more frequently depending on the illness.

Are there volunteers who visit my child?
Yes, we have volunteers who come to play, cuddle and read to your child.

What type of training does a Certified Nursing Assistant (CNA) have before taking care of my child?
A certified nursing aide must successfully complete the New Jersey curriculum for Nurse Aide in Long Term Care Facilities Training and Competency Evaluation Program (NATCEP) or New Jersey Curriculum for Personal Care Assistants (PCA) to work in a long-term care facility or Assisted Living Facility, respectively. The NATCEP training course is 90 hours, consisting of 50-classroom hours and 40 clinical hours in a New Jersey licensed long-term care facility for Nurse Aide. The PCA training course is 85 hours, consisting of 69-classroom hours and 16 clinical hours in a New Jersey licensed assisted living facility, comprehensive personal care home or assisted living program.

How is Children’s Specialized Hospital’s Long Term Care center rated?
Children’s Specialized Hospital Long Term Care Centers are 5 star rated. There is an official State level inspection and quality rating conducted annually. The overall rating is a combination of the health inspection rating, the staffing rating, and the quality measures rating. Analysis was conducted on these three data sources and each of these ratings was combined into one overall rating. When looking at the five-star ratings, more stars are better. Five (5) stars are the most a long-term center can get. One (1) star is the fewest.

I have just moved my child from a Rehabilitation Hospital to Children’s Specialized Long Term Care Center. Can you provide me with information about what is the definition of Long Term Care versus Rehabilitation?
Rehabilitation is a treatment or treatments designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible. The purpose of rehabilitation is to restore some or all of the patient’s physical, sensory, and mental capabilities that were lost due to injury, illness, or disease. Rehabilitation includes assisting the patient to compensate for deficits that cannot be reversed medically.
Long Term Care Center provides dignified and tender loving care for children with long-term medical needs. The therapeutic atmosphere coupled with specialized medical and nursing care and a diversity of activities is designed to maintain each child’s abilities and encourage the maximum potential in each child.
How are my child’s therapy goals different in a Rehabilitation Hospital versus Long Term Care center?

Rehabilitation Hospital Care is primarily therapy focused with goals related to restoration and/ or improved function.

Long Term Care is a maintenance/home model with primary focus on nursing and activities with goal to maintain function and provide quality of life.

I have just moved my child from an Acute Care hospital to Children’s Long Term Care center. Can you provide me with information about what is the definition of Long Term Care versus Acute care?

Acute Hospital care is primarily medically focused with goals related to medical treatments/outcomes.
If your child is coming to us from an acute care hospital, this means that he/she is now more medically stable...this is good news.
In the Acute Care (critical care setting), your child may have had more intensive nursing care than will be provided here; we can assure you that we have an entire team (doctors, nurses, patient care coordinators, therapists and others) working together with you and your child to insure that your child stays safe and receives quality care.
Long Term Care Center provides dignified and tender loving care for children with long-term medical needs. The therapeutic atmosphere coupled with specialized medical and nursing care and a diversity of activities is designed to maintain each child’s abilities and encourage the maximum potential in each child.

In the bed hold policy, I noticed that you talk about a licensed Medicaid bed. What does a licensed Medicaid bed mean?
It means that if Medicaid is paying for your child to be in Children’s Specialized Hospital Long Term Care center then they are in a Medicaid licensed bed. If your private insurance is paying for the bed, then the Medicaid licensed bed policy does not pertain to you.

What does the 10- day Medicaid bed hold regulation mean?
Medicaid requires that long-term care providers keep a bed open for readmission for a period of 10 days. After 10 days they require that the bed must be open to other patients.

When does the 10- day bed hold begin?
The 10-day bed hold begins the day your child leaves Children’s Specialized Hospital.
If my child is in another facility for over 10 days, what is the procedure to be readmitted?
If your child is in a Medicaid bed in Children’s Specialized Hospital they must be placed first on a Children’s Specialized wait list for any open bed. Readmission, beyond the 10-day bed hold period, will be determined based on
- Continued eligibility of the child to qualify for Long Term Care nursing services, and
- Availability of a bed.

What if no bed is available for my child at Children’s Specialized Hospital, what are my options?
- Your child might remain at the current facility until a Pediatric Long Term care a bed is available
- If a bed is available at another Pediatric Long Term Care facility and your child meets that facility’s admission requirements, your child will be admitted there, with the option to be admitted back to Children’s Specialized Hospital when a bed is made available

If there is no bed available, will I have to take my child home until a bed is made available?
- If your child qualifies for Long Term Care nursing services, then those services will be made available.

What are a DNR and DNH?
DNR is Do Not Resuscitate that means that your child will not be resuscitated if they suffer respiratory arrest.
DNH is Do Not Hospitalize that means that your child would not be transferred to another hospital for care.
In the case of both advanced directives your child would be kept comfortable with medications at Children’s Specialized Hospital.
Contacts Information and Names of Individuals who care for your Child

**Nurse Manager and Nurse Practitioner**

Imelda Shoola, Nurse Manager  
908-301-5464  
ishoola@childrens-specialized.org

Grace Page, Nurse Practitioner  
908-301-5417  
gpage@childrens-specialized.org

**Therapy Manager – Both Centers**

Rayna Correia, CTRS  
Manager of Recreational Therapy/Childlife & Long Term Care Therapy Services  
Children's Specialized Hospital  
908-233-3720 x5362  
RCorreia@childrens-specialized.org

Carolyn Romond, CTRS  
Therapy Supervisor Toms River  
732 914-1100 x  
cromond@childrens-specialized.org

**Patient Care Coordinator/Social Worker**

Mountainside  
Evelyn Lozada-Sipe  
908-301-5591  
ELozado-Sipe@childrens-specialized.org

Toms River  
Maura Hines  
732-797-3833  
mhines@childrens-specialized.org

**Respiratory Care Team**

Lori-Ann Ligon Director of Respiratory Care  
lligon@childrens-specialized.org

**Spiritual Care**

Mountainside  
Ann Shamy  
908-233-3720 X 5060  
ashamy@childrens-specialized.org

Toms River  
Cherryl Baker  
732-797-3800  
cbaker@childrens-specialized.org

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### Family Faculty

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<thead>
<tr>
<th>Mountainside</th>
<th>Toms River</th>
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<tbody>
<tr>
<td>Linda Wadell</td>
<td>Jessica Krill</td>
</tr>
<tr>
<td>908-301-5534 x5346</td>
<td>1-888-244-5373 x5373</td>
</tr>
<tr>
<td><a href="mailto:lwadell@childrens-specialized.org">lwadell@childrens-specialized.org</a></td>
<td><a href="mailto:jkrill@childrens-specialized.org">jkrill@childrens-specialized.org</a></td>
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