



MFTD Waiver Families

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CPS Nursing for Children who are Medically Fragile and Technology Dependent

Currently, children who are medically fragile and technology dependent miss tremendous amounts of school because nursing is unavailable in the school environment. When nursing is available, nurses are often not trained on pediatric technologies, such as tracheostomies, ventilators, feeding tubes, central lines, and enteral/parenteral pumps, putting children's lives at risk.

Children who are medically fragile and technology dependent typically participate in the Medically Fragile, Technology Dependent (MFTD) waiver administered by Specialized Care for Children (DSCC). This population also includes a small number of non-waiver children who require nursing. All of these children require skilled nursing services 24 hours a day, and virtually all require individual 1:1 nursing.

The following suggestions are designed to help increase the availability of nursing services in the schools for this population, while also preserving the health and safety of students.

- 1. CPS should first attempt to individually contract directly with the nursing agency currently caring for each individual child.** This will allow for continuity of care, as the same nurses who care for the child at home will continue caring for the child at school. The number of approved agencies in the region is not large and most children in Chicago use just a handful of agencies.
- 2. In some cases, families bring their home nurses to school with them. Any home nurse paid for via the DSCC home care program (MFTD waiver or non-waiver) should be allowed to care for a child in any school.** These nurses are already thoroughly background checked, fingerprinted, and subject to other state and agency regulations that ensure they are safe to work in school environments.
- 3. While families can use nurses paid for through Medicaid via the DSCC home care program, they cannot be required to do so if they are unable to find nurses or choose not to use their home nurses.** CPS is ultimately required to arrange nursing for all children who require it. Because of severe shortages of home care nurses, CPS will likely need to use a variety of agencies and strategies to find nurses for all children who require 1:1 nursing. Agencies should be chosen from the list of DSCC certified and

approved agencies whenever possible, as these agencies have specific experience with pediatric medical technology.

4. **Nurse pay should be stratified based on the acuity of the child.** Suggested groupings:
 - a. Feeding tube only or oxygen only.
 - b. Complicated feeding tube plus respiratory support; or central line with IV nutrition.
 - c. Tracheostomy without ventilator.
 - d. Ventilator.

5. **Any 1:1 nurse must be given comprehensive training provided by a CPS nurse, a home nurse, or a parent on the child's needs.** Training must continue until the nurse is able to perform his/her duties adequately and independently.

6. **If CPS provides a 1:1 nurse, whether a CPS nurse or an agency nurse, the nurse must be prepared to meet all of the child's needs, including personal care and nursing care, as would be typical of a home care nurse.** These services might include diaper changes, transfers, placing a child in positioning equipment, and oral feeding. While aides may assist in performing some of these duties, the nurse must be on hand to ensure the medical safety of the child throughout the procedure.

7. **Any 1:1 nurse provided by CPS or a CPS-contracted agency must care for the child at all times from the moment the child leaves the home until the child is returned to the home.** If a nurse is given a lunch or other break, another trained 1:1 nurse must be provided to the child during the break. A nurse must attend children who require 1:1 nursing at all times.

8. **If a nurse is unavailable, an approved home caregiver (parent or guardian) must be permitted to accompany the child to school, including on the bus, so the child is not denied a day of education.** The parent/guardian will need to go through the CPS volunteer procedure to become an approved volunteer.

9. **A pool of backup nurses must be available in the case of a nurse absence.** The nurses must be fully trained ahead of time on the individual students they might serve.

10. **CPS should obtain the child's current Plan of Care (485 Form) from the child's parent, nursing agency, or DSCC.** The Plan of Care should be provided to all nurses assigned to the child PRIOR to meeting the child. This will keep the child's care plan consistent from home to school, in addition to providing detailed information about the child's needs, medications, and technologies.

- 11. Nurses should never be required to perform the duties of an educational aide or SECA or assist other students in the classroom.**
- 12. Children receiving 1:1 nursing should automatically be approved for the Home and Hospital Instruction program.** Intermittent services must be made available on any day that CPS cannot provide a nurse at school. Children should be pre-approved for a period of at least one school year.
- 13. Children with central lines in use during the school day must be provided with RNs per state regulations.**
- 14. CPS should ensure that reimbursement is maximized by billing Medicaid for nursing hours.**

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MFTD Waiver Families is a support and advocacy organization for families of children who receive home nursing in the state of Illinois through the MFTD Waiver and related programs. For more information, contact founder, Susan Agrawal, at mftdwaiver@gmail.com or 773-583-0135.