

Some Suggestions for Letters of Instruction Regarding Disabled Children

Letters of instruction (sometimes called letters of intent) from parents with respect to disabled children are designed to provide critical information to others who may need to care for the child when the parents are no longer available. Such letters should be revised and updated regularly as the child gets older and as things change in the child's life. Such letters will not be legally binding but will provide the necessary background information to make a transition in care as smooth as possible. They can be a page or two or consist of a ring binder of resource materials and backup documents.

- Child's full name, address, social security number, birth date
- Description of the disability and its effect on child
 - how profound is the disability
 - what activities of daily living are affected
- Medical history of the child
 - related to disability
 - related to general health, such as immunizations, allergies, etc.
 - location of medical records
- Names, addresses, phone numbers, e-mail addresses of key persons, with an explanation of why they are important to the child
 - important friends and relatives
 - physicians, therapists, dentists, other health care providers

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- care givers, teachers, religious leaders, scout masters, employment supervisors
- trustees, legal and financial advisors
- persons to be appointed guardians
- Child's likes and dislikes
 - favorite foods and foods disliked
 - pets, playmates, neighbors
 - identity and location of favorite toys, comfort blankets, clothes, and similar items
 - sports, games, and activities
 - favorite T.V. shows, music, videos, entertainments (*e.g.*, zoo), etc., and favorite sports or entertainment personalities
 - passwords or similar information for access to child's online activities, such as for game, music, or video accounts
 - things that bother the child
- Description of child's daily routine
 - time to wake and morning rituals and routine
 - school, playground, clubs or organizations, job or volunteer work (seek input from teachers and others)
 - mealtimes and routines
 - medications taken (location, dosage, and time)
 - bedtime and nightly rituals (*e.g.*, story time) and routine
- Communication
 - words or phrases with special meaning to child, the meaning of which may not be readily apparent
 - any other aids to communication with child
 - ways to calm child

- Resources available to child
 - trusts, conservatorships, or similar private resources
 - medical insurance (plan numbers, etc.)
 - government benefits
 - location of cards or benefit documentation
- Plans for the future
 - hopes and desires of the child
 - plans in place and progress of implementation (*i.e.*, individual education plans)
 - location of estate planning documents
 - funeral arrangements or instructions
- Custody and visitation (if applicable)
 - location of divorce or custody decrees
 - visitation schedules
 - any special concerns