

Your Child is Turning 18 - Now What?

A Primer on Guardianship and Surrogate Decision Making for the Parent of a Special Needs Child

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You have protected and advocated fiercely for your child with special needs, almost since the day she was born. You fought insurance companies, school systems, you name it; all to get your special child the best possible education and care and to give her the chance to be all that she can be. Time flies, and suddenly your little girl turns 18 and she becomes emancipated as a matter of law.

The law may think that, now that she is 18, she is suddenly ready to take care of herself and make all of her own decisions. You know better. However, suddenly the school can't discuss her education with you and her doctors won't discuss her medical condition. Now that she is legally an adult, you are suddenly cut out. They can't talk to you unless she has given them her consent. What do you do?

You have several options to consider. There are a number of alternatives that are available, ranging from full guardianship to a simple power of attorney and health care proxy. Which option makes sense for you and your special child depends in large part on the degree of disability affecting your special child.

Guardianship

If your special child has severe disabilities which affect her mental capacity so that she cannot manage her own affairs, a full legal guardianship may be a good option. A full guardianship, sometimes referred to as guardianship of the person and property or a plenary guardianship, gives the guardian total control over the person and property of another individual, generally called the ward. If you are appointed the full legal guardian for your special child, you control every aspect of that child's life for as long as you are the guardian. You can deal with doctors, government agencies, courts, financial institutions, and others on behalf of your child.

Full legal guardianship is not something that is obtained lightly, since, once you are appointed as full legal guardian of your child, she loses her rights to act independently. In order to protect the rights of a potential ward, a full legal guardianship can only be obtained by going to court and asking a judge to appoint a guardian. The specific procedures vary from state to state; however, there are some common themes that recur in guardianship proceedings throughout the country.

The proceeding is usually commenced by your attorney filing a written request (sometimes called a petition or a complaint depending on your state) to a judge in your area that has authority to appoint you as guardian. The request asks the judge to appoint you as legal guardian of your special child. As part of your initial request, you will usually be required to submit proof to the judge that your special child is incapable of managing her own affairs on a day to day basis. This is gen-



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erally done by providing the judge with sworn statements from qualified doctors, detailing the nature and extent of the disability and rendering the opinions of the doctors that the proposed ward is not able to manage her own affairs on a daily basis. You will also provide your own sworn statement, giving the judge your experience in caring for your child, and why you think a full guardianship is needed.

The judge will set the matter down for a hearing, at a date the judge picks. In many states the judge will also appoint an independent third party, often a local attorney, to represent the interests of your child in the proceeding. This person, sometimes called a guardian ad litem, will usually undertake an independent investigation into the situation, meet with your child, review the doctors' statements and talk with you and your attorney. The guardian ad litem will file a written report with the judge giving the guardian ad litem's opinion on whether a full guardianship is appropriate. The guardian ad litem will file a report with the judge at some point before the day of the hearing. This is a good safeguard to protect the proposed ward, since you are in effect asking the court to take away her civil liberties when you ask the court to appoint you as full guardian over your special child.

When the hearing date comes, you and your attorney will attend the hearing, as will the guardian ad litem. At that hearing, the judge will listen to your evidence. In most cases, your doctors do not have come in and testify. The judge will accept their sworn statements. You will likely have to testify as to why you think you should be appointed guardian. You will also have to satisfy the judge that you understand the full impact of the role you will undertake. This is normally not difficult; after all, you have been acting as your child's guardian all her life. The only real difference is that she is now 18.

The judge will ask the guardian ad litem to confirm that full guardianship is appropriate. Assuming there are no new

developments since the guardian ad litem filed the report, the guardian ad litem will generally confirm the appropriateness of the appointment. If the judge is satisfied, then an order appointing you as full guardian will be issued. You will have to report back to the court (usually annually) regarding the status of your child/ward, including providing a report on how you have handled the child's financial matters. While this may seem a bit of a nuisance, this is an important protection for your child. You only have to read the papers to see incidents where a guardian abused the ward to know that such protection is very valuable for your child. After all, you may not be around forever. Someday, someone else may have to step up to act as guardian for your child. You would certainly want the court to be looking over that person's shoulder, watching out for your child!

Sometimes, the special child may not be so incapacitated as to require a full guardianship. For example, if your child is able to attend a regular school, then a full guardianship may not be available to you since a child that can handle school activities may not be so disabled as to be unable to handle any of her own affairs. She may only have a mild disability, and be able to make some decisions for herself but, for example, cannot manage her own assets. In that case, a more limited guardianship over only her assets, but not her person, may be appropriate.

Many states allow for such partial or limited guardianships. In those states, you may be able to request more limited authority over your child. Courts in those states that allow limited guardianships try to create a guardianship that gives you authority over areas where your special child needs protection, but allows her to retain as much autonomy and control over her affairs as is possible. The procedures for seeking limited guardianship are much the same as in a full guardianship, except that the scope of authority you request is more specifically crafted for the abilities of your special child.

Alternatives to Guardianship

Just because a child has disabilities does not automatically make her a candidate for guardianship. A judge will not appoint a guardian for a special child with disabilities who otherwise has sufficient mental capacity to manage her own affairs. However, if your child has enough mental capacity that a guardianship is not appropriate, but still needs help in managing her affairs, there are several alternatives.

Some states have a procedure, sometimes referred to as a conservatorship where a conservator is appointed to manage the financial affairs of an otherwise legally competent adult who by reason of advanced age, illness or physical infirmity, is unable to manage his or her own financial affairs (such a person is sometimes called a conservatee).

The process for seeking appointment as a conservator is similar to the process for seeking appointment as a guardian of the property, with one key difference: unlike in a guardianship proceeding, in a

conservatorship, there is no requirement that the conservatee be found legally incompetent, only that she is unable to manage her financial affairs due to advanced age, illness or infirmity. As a result, the conservatee does not lose any of her civil rights, since there has been no determination of legal incompetency. The conservatee may consent to the appointment of a conservator to manage her financial affairs. In fact, the conservatee may actually start the conservatorship process herself. A conservatorship may be a good alternative to guardianship of the property where the child is mentally competent but there are concerns regarding his/her ability to manage money.

Another alternative to consider once she turns 18 is for her to sign a Durable Financial Power of Attorney authorizing you to handle her financial affairs. A Durable Financial Power of Attorney is a document that gives another person the right to manage and dispose of your property in the same manner as you could. The recipient of the Power is called the "attorney-in-fact." If the child with special needs has sufficient mental capacity, she can grant power of attorney to one or both of her parents. This will allow the parents to handle the child's financial affairs without the need to appoint a guardian or a conservator.

Keep in mind that, even if the special child grants her parents the authority to act as her attorneys-in-fact, this does not prevent her from taking actions on her own behalf. In addition, since she has sufficient mental competence to grant a Durable Power of Attorney, she can also revoke the Power it at any time. Thus, it is important that parents and child maintain a good and trusting working relationship.

The situation differs when dealing with medical decision making. As a general rule, if a person has the mental capacity to make medical decisions on her own behalf, the person will make her own decisions. This is equally true for the child with special needs. If she has sufficient mental capacity to make her own decisions regarding matters of health, the call will be hers. This does not mean that the parents cannot participate in medical decisions. However, in order to do so, the parents must have the child's permission to discuss her medical matters with doctors and other health care providers. The child can simply sign a consent allowing the child's medical caregivers to give medical information to the parents.

The child with special needs should also appoint one or both of her parents as her health care representatives to give them the clear right to make medical decisions for her if she becomes incapacitated. She does this by signing a Health Care Proxy, a document similar in concept to the Durable Financial Power of Attorney, except that it relates solely to health care. The person to whom the decision-making power is given is sometimes called the "health care representative" or "health care proxy."

In similar fashion, the special child can grant her parents permission to interact with her teachers and other persons

involved in her education in connection with her individual education plan and transition planning. Most schools have forms available for the child to sign upon turning 18.

A note of caution about seeking guardianship or conservatorship: although you can go to court without an attorney, the rules and procedures for obtaining guardianship or conservatorship can be

quite complex. This is not a good area for the uninitiated. However, if your child is developmentally disabled, your state or local office serving persons with developmental disabilities may assist you in obtaining guardianship for your child. A developmental disability is generally defined as a severe disability which started at birth or developed during childhood, which the disability will continue indefi-

nitely and seriously adversely affect the child's ability to function in life.

Summary

In summary, as your special child approaches 18, you should: (1) evaluate what level of independence she can achieve in her lifetime, (2) consider to what extent a full or partial guardianship may be needed

and begin the process, and (3) if a guardianship is not appropriate, make the necessary arrangements for your special child to give you her power of attorney and appoint you as her health care representative. In this way, you can continue to support and protect your special child.