



# Parents' Declaration of Independence & Bill of Rights

*The inalienable rights of parents of children with disabilities.*

By  
Sol  
Gordon, Ph.D.

**T**he following rights allow parents to determine if they are doing right by themselves; whether they are doing the right thing. The first four rights constitute the basic Declaration of Independence. Once these are realized, or at least are in process, the next 10 rights (The Bill of Rights) become possible.

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#### DECLARATION OF INDEPENDENCE

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The first right is to mourn, to feel sorry for yourself, to agonize over the question, "Why me?" The right to work through all of the could ofs and should ofs in your life is part of this. Have death wishes. Blame God, or question why He has forsaken you. And then as soon as possible *for you*, come to the conclusion that you will never know the answer to most of your important questions. Now you have to do the best that *you* can and get on with your life.

It's that simple. Not everything worthwhile is complicated. But almost everything worthwhile is difficult to accomplish.

You have the right to feel that you are doing the best you can, that you are coping with an enormously difficult situation the best way you know. But it is essential not to judge anyone else on the basis of your expectations for yourself. Your spouse may be doing the best he or she can by simply

returning to everyday routines, work, for example. A sibling might not be anywhere near meeting your expectations or requirements.

What constitutes your timing might not be anybody else's. By being a model and inspiration, you accomplish a great deal. By being a nag, by wallowing in self-pity, by being preoccupied with the tragedy, you will undermine what you need to accomplish.

You have the right to begin selfishly organizing your life to your own satisfaction. More than ever, you need hobbies, distractions, excitements. At no time previously did you ever need opportunities for leisure and pleasure as much. Do the things you enjoy; however much this is contrived; however much you feel that you can't afford the time or the money; however much you feel your neighbors will misinterpret what you do.

The final absolutely essential right is to have a sense of humor. Nobody can survive a tragic situation without eventually developing a sense of humor. Family life can become grim, with everyone walking on tiptoes, and laughter can be misunderstood at these times.

I shall never forget the story of a 15-year-old boy with a learning disability being asked to take out the garbage. His

response was "I can't take out the garbage -- I'm brain injured." And his mother's response was, "If you don't want to be brain injured twice, you had better take out the garbage." This happened in a lively, active home where people were more than just survivors. They live a good life.

If you don't have a sense of humor, fake it. When you hear other people laugh, laugh with them. You will be surprised, in a year's time you will have your own sense of humor.

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## BILL OF RIGHTS

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### 1. *The right not to be blamed.*

How devastating when a teacher or professional or anybody suggests that the reason why your child is in trouble is because of your guilt, or your inadequacy, or your psychological problems. Of course, in some cases there is an element, however small, of truth in some of the accusations, but rarely is it the main problem, and rarely is the criticism helpful. The right also applies to not being intimidated by professionals simply because of their presumed superior knowledge or status.

### 2. *The right to understand what's going on.*

No parent should leave a conference with school personnel, mental health professionals or physicians without a complete understanding of what they are talking about. If they use abbreviations for tests, or give a medical diagnosis in jargon you do not understand, it is *always* appropriate to ask for an explanation in language that you understand thoroughly.

### 3. *The right not to be exploited.*

It is hard enough having to cope with the daily tasks and troubles of parenting. Imagine having to pay exorbitant rates for help from insensitive staff, and not getting your money's worth for the precious money you have to spend.

### 4. *The right to accept help without apology.*

If any friend or relative asks you if there is anything they can do for you, always say yes. You may lose 90 percent of your friends and relatives that way, but those who stick by you, you can count on. There is usually something somebody can do for you: baby-sit for an hour or two, take your child to the movies or ball game,

run an errand for you. You must, however, expect in advance that most people's offers of help are not genuine. If it turns out otherwise for you, I certainly do not mind being wrong about this prediction.

### 5. *The right to make decisions.*

Parents are invariably under pressure to accept the decisions of experts. It is your child and your responsibility. It is up to you to make the decisions, even if you disagree with any combination of experts.

### 6. *The right to be angry.*

Most of the progress that has been made in the field of the care and management of children with disabilities has resulted from the work of angry parents. Rarely can you count on professionals to take the initiative for progressive innovations in your child's best interests. It does occur in the realm of political advocacy, but rarely when it comes to the daily management of children with severe disabilities.

### 7. *The right to a normal family life.*

Having a child with a disability should not exclude anyone from family celebrations, parties or the whole range of what constitutes the joys and travails of family life. This is not to suggest that everybody or anybody will feel comfortable in the presence of or interacting with your child. The failure to appreciate the high level of discomfort that the average person has relating to people with disabilities certainly inhibits their acceptance in the society. Talk about the discomfort. It is not a plea for pity; it is simply an introduction to eventual integration.

### 8. *The right to live a part of your life that does not include your child.*

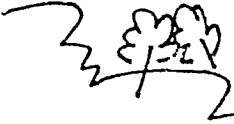
There is a powerful need for parents to be on their own, to get away from everything, to go away on vacations without their children. No healthy, mature family functions well in a posture of togetherness all the time. Sisters and brothers may resent the need to play with and relate to the child with a disability to the exclusion of their own special needs.

### 9. *The right to fake it from time to time.*

From time to time it is perfectly all right to present the image that everything's OK, especially with people you do not care about that much.

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Just as it is appropriate to express anger at times, it is also OK to squelch it. Recent evidence suggests that unexpressed anger is not necessarily harmful and is sometimes even beneficial. Just because we are angry does not mean that the other person is ready and able to receive our anger.

William James suggested that "Wisdom is learning what to overlook." And sometimes faking it creates the best possible conditions for improvement of a really grim situation.

### 10. The right to expect miracles.

It is a right not to give up, not to operate on the assumption that our current scope of knowledge is a verdict of doom. It is incredible how many people have survived "death sentences." Look at the progress that is being made today with the help of computers.

### MAKING IT WORK FOR YOU

You get no points for being the parent of a child with a disability. We need to acknowledge that for you everything in life is harder, more costly in every sense. Comfort or peace of mind will not come from comparing yourself with anyone else, even if you objectively know that many other people's troubles are worse than yours.

The biggest problems develop when the whole family becomes disorganized around the existence, care and management of a disabled child (to say nothing of more than one disabled child). However, families can organize and support each other, especially in situations where 1) once unified families are threatened with breakdown, and 2) families are hanging together because of determination and commitment, but lack the previous sparkle, spontaneity and joy of family life.

Not all of my suggestions will work for you, but some might, and these will add to the excitement of your strength. The hardest thing to recover from is anger. Yet anger diluted with forgiveness has a special alchemy — it becomes determination, if not courage, to do the best you can. Accepting your anger with a sense of forgiveness helps to reorganize your family, put your own life into orbit and give priority to yourself no matter how much you need to attend to your spouse and children. More than anything else, do not isolate yourself, no matter how miserable you still feel.

The very best test of whether you are working in the right direction is the amount of energy you have. Discounting extreme situations, energy is mainly a psychological phenomenon. How often have you experienced a period of exhaustion that instantly turns into boundless energy upon meeting someone you care about, or upon receiving an unexpected surprise visit or phone call, or upon learning something new.

Haven't you also noticed that mature love experiences are energizing, while immature ones are



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*Knowing that the odds are against you makes it even more compelling for you to do the best you can and then get on with your life.*

exhausting? If you are working toward maximizing autonomy for your child; if you believe that your past is not your potential; if you have some faith or optimism; if you are determined to consider the needs of the whole family; you do not have to accomplish very much before you notice that you have a great deal of energy.

Remember that unhappiness itself is alienating, not only because people shun those who are unhappy, but also because people who are miserable often resent other people's happiness. The vitality of healthy children reassures parents about their marriage as well as themselves. When there is something wrong with the child, the whole enterprise of marriage and family is threatened. Knowing that the odds are against you makes it even more compelling for you to do the best you can, and then get on with your life.

#### ADDITIONAL RIGHTS

*The following are 15 additional rights, one privilege, one source of pride and one inevitable consequence. These rights are for you to dwell upon, to discuss with your spouse and to bring up in family meetings. Then you can create many more of your own.*

1. Not to devote your entire life to the cause, but freedom to devote as much as you want, or to get away from it for a while.
2. Freedom to take your time in deciding what to do. The right to shop around for competent professional help. The right not to accept advice or even comfort, especially from people who say things like, "You think you have troubles?"
3. The right to intervene on behalf of your child, to arrange parties and rendezvous with friends.
4. The right to consider institutionalization, even if it goes against the trend.
5. The right to feel that it is not God's will, nor is it a punishment.
6. The right to feel that it is God's will (but you still have it figure out what *is* His message).

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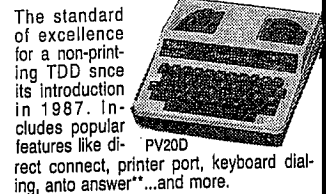
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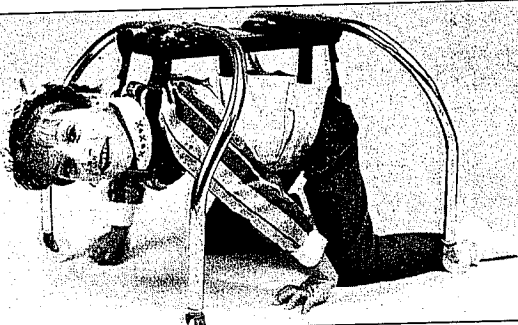
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7. The right to send your child to a camp for the summer, even if the child does not want to go. It is amazing how 95 percent of them end up with a really good experience.

8. The right to good and bad moods. The right not to be perfect (to have hostile thoughts). It is all right to feel bad and mourn from time to time.

9. The right to become a student, such as to learn sign language, or to become a specialist in a field, even if your motive is initially to help your own child.

10. The right to have all the privileges of your religion.

11. The right to expect your child to learn to live well with the family.

12. The right to joke, fool around and be silly.

13. The right to find some use out of all the sorrow, whether it is writing a book, poetry or understanding the needs of other people in a more sensitive and compassionate way.

14. The right to pay attention to your own health. Become a health nut.

15. The right to be a family that sticks together, no matter what.

16. The privilege — to use your experiences to be helpful to other parents.

17. The source of pride — be proud of your accomplishments.

This brings us to the inevitable consequence:

18. Enabling your child to also be proud.



Sol Gordon received his doctorate in psychology from the University of London (England). He was professor of child and family studies and director of the Institute for Family Research and Education at Syracuse University from 1970-1985 and is now Professor Emeritus. Dr. Gordon lives in Belmont, Calif. and devotes his time to group lectures and seminars on various topics. He is the author of 15 books, including *When Living Hurts*, (Dell Paperback, 1988).