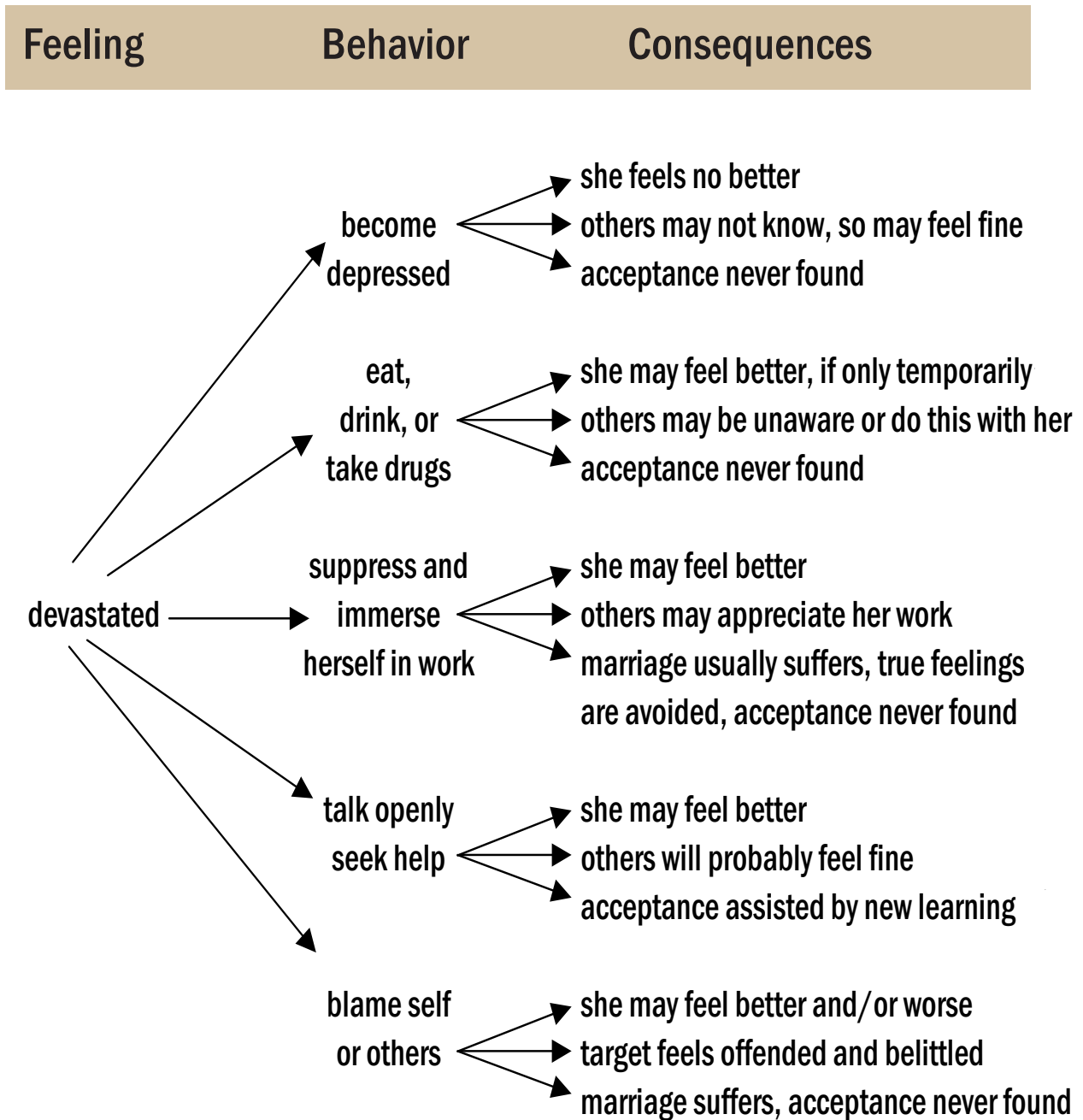


Table of Contents

Preface	v
Introduction	viii
Chapter 1 Avoiding Blame	1
Chapter 2 Support and Guidance	17
Chapter 3 Affordable Child Care	29
Chapter 4 Money Matters	39
Chapter 5 Time Alone	49
Chapter 6 Effective Communication	63
Chapter 7 Child Rearing and Discipline.....	85
Chapter 8 Sex, Affection, and Intimacy	97
Chapter 9 Potentials.....	107
Appendix 1 A Six-Week Program for Couples.....	121
Appendix 2 About Divorce.....	137
Appendix 3 A Workshop for Support Groups	145



From comparing these alternatives, it becomes apparent that blaming is a behavior that is an effort at escaping the pain of one's feelings. The degree to which it works may vary with the individual, but there will always be downsides: the people who receive the blame are never likely to be comfortable with it; it will never lead to true and lasting "coming to terms" with the disability; and it may serve to distance the person from his or her family and only add to the hardships faced by the child. One parent said it so well:

There's a kind of tragic irony to this in that the best possible thing for the child is that their family should stay together, that the child should live in the warm, supportive bosom of a reasonably happy, stable, together family. And yet, the parents' marriage gets shoved to the back burner and gets relegated to the absolutely lowest priority when, quite probably, it should be the highest.

When the parents allow themselves to become stuck in negative thoughts and feelings, in blaming themselves, each other, life and God, yesterday and tomorrow, what progress is being made? How is anyone served and benefited? There are alternatives.

Weaken or Strengthen?

One parent made a commitment that the news of her child's disability would not be allowed to destroy her marriage:

I am a firm believer that if you already have a weak, unstable marriage, any devastating news will make it topple. But if you have something special, something strong, then the news can possibly weaken it, but not destroy it. Maybe someday strengthen it. "They" (who are "they" anyway?) estimate that up to half of all couples divorce after the diagnosis. We will not be one of those statistics.

Recommendations

When parents at support group meetings were asked where parents can go for guidance, information, and support, the following suggestions were made:

1. **Join a support group right away.** *Don't go it alone, and don't wait for a crisis before seeking help.*
2. **Let it be known that you need help** or have questions. *Get out of the house, and seek out help and support from friends and others.*
3. **Reach out** to school counselors, pastors and your church community; join Internet discussion groups; call Mental Health and Mental Retardation (MHMR) or other community services; find out what grant-funded services are in your community, such as "Parenting Cottage." *Note that specific programs vary from state to state, and even from county to county.*
4. **Form a mentoring relationship** with other parents who have been through the same kinds of things, and ask if you can call them when you have a problem or question. *Although schools, doctors and agencies will not usually give out the names of such parents, they may be willing to pass your name along to them if you request it.*
5. **Get involved in activities** where you can connect with other parents, such as "Special Olympics."
6. **Be proactive:** *if there are services that you need, encourage people to get it started—maybe through a church, a parenting group or school volunteers.*
7. **Don't let your family become isolated** from other families. *If a child doesn't have friends, it is often harder for the family to have friends too. Sometimes parents avoid being involved with friends and family because they are ashamed of their child, or maybe they are afraid of being an imposition on others. They need to get over that—they need to get involved and to know how important it is.*