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Chapter 1 : Education of Retarded Children: A Review for Physicians | JAMA Pediatrics | JAMA Network

Family Crisis and the Decision to Institutionalize the Retarded Child. CEC Research Monograph, Series A, Number 1.

Advances in medical care have made it possible for your child to have a normal or close to normal lifespan. Maybe you are beginning to feel your age. Maybe your health and strength are failing. Your child has been the center of your life for decades and depends on you to be the buffer between him and the world. One day you wake up and realize you are faced with a new and frightening dilemma: Who will provide the same love and care when you are too old or frail or sick to manage or when you are gone? You have given your child the gift of a loving family life well into adulthood. You do have at least some choices about how to best provide care for the adult child left behind. You are not alone if you find this enormously difficult even to think about. Maybe it breaks your heart to think about how difficult it will be for your child to adapt to a new situation. Or, like many parents, you are so overwhelmed by the thought of dealing with the bureaucracy called human services you are finding it hard to get up the energy to put plans in motion. Without a plan, your child could be emotionally traumatized by losing everything at once parent, home, and all that is familiar if you suddenly become disabled or die. Loving your child now means beginning the process of letting go. Your child needs your support in transitioning to whatever will come next. You need the peace of mind, and the relief, that can come with knowing that your child will be safe and cared for. Planning for the future is a lengthy process. With the support of family and other parents and with some good professional help, you can meet this one too: Here are some of the things you will need to do or think about: Contact the local agency that oversees services for the intellectually disabled. Often there are case managers who can help you learn what is possible. Different states and communities have different services and different residential options. Case managers also often are able to refer you to parent support groups, family therapists, or other professionals who can help you and your child understand and manage the challenges of this stage of life. It may be disappointing to find that no family members can guarantee that they will take your child in. It is very, very expensive to replace you. Maintaining and staffing a residential program probably costs more than you think. Before you consider creating your own program for your child, make sure that you have a realistic understanding of just how much money it will take and what is involved in managing it. Estate laws vary from state to state. So do the rules and regulations for government benefits. Sometimes having money or property in his or her name will mean that your child is ineligible. Work with an attorney and accountant to protect your child over the distant future. Wait-lists for residential placement often are very long. In this sense, an adult child with intellectual disabilities is no different from any other child who is getting ready to leave home. It may be easier, for example, to do his laundry. But if he is capable of learning how to do it on his own, he will develop more self-confidence and he will be easier to place. When people are comfortable around others, they are less upset when they must move to a new living situation. What will you do to fill the big hole left behind when your child leaves? You may be rusty at being social or doing things you once enjoyed. Consider seeing a therapist if you find it hard to manage your feelings. You may be scared. Taking the next step is a lot to think about. Embracing the challenge of planning for the future will. Marie Hartwell-Walker is licensed as both a psychologist and marriage and family counselor. She specializes in couples and family therapy and parent education. She is author of the insightful parenting e-book, *Tending the Family Heart*. Check out her book, *Unlocking the Secrets of Self-Esteem*. Retrieved on November 13, , from <https://>

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Chapter 3 : the autism crisis: Instant institutionalization

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Chapter 4 : Future Planning for Your Intellectually Disabled Adult Child

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