

Decision-Making for Adults with Intellectual Disabilities

What are the decision-making options for adults with intellectual disabilities? Is guardianship and conservatorship inevitable? If you've been watching this series you know the answer to that question is no. So, what are the alternatives for families?

Let's look at Jimmy as an example. Jimmy was born with Down syndrome. When he turns 19, Jimmy is considered an adult in Alabama. And like all adults in Alabama, he has the right to make his own decisions. But Jimmy's parents are told they need to get a guardianship for Jimmy. Does Jimmy need a guardian to make his healthcare and other decisions? Let's apply three principles we've learned about guardianships to help answer the question.

Number one: Is Jimmy incapacitated? Does he meet the legal definition required for guardianship? The test has two parts. First, does Jimmy have a mental illness or condition, physical illness or disability? The answer to the first part is yes. The second part is this: Does Jimmy's condition prevent him from communicating his decisions, or is he not able to make responsible decisions? That's where it becomes difficult, and each person is different. As we discussed in video two, determining capacity is not a one-size-fits-all approach. Every person has different decision-making abilities about different things. And, there are many assistive technologies available to help Jimmy communicate, if that is the issue.

Number two: What are Jimmy's abilities and where does he need help? Supported decision-making may work for Jimmy. Jimmy's parents and others -- his supporters -- can help Jimmy understand the choices he has and weigh the options so that Jimmy can make decisions for himself. Jimmy may be able to provide informed consent to undergo a medical procedure. Jimmy's doctors can talk to him about the risks, benefits, and alternatives of a given procedure. Jimmy's parents can explain the procedure to Jimmy, and if needed, help communicate his decision back to his doctors. Supported decision-making would allow Jimmy to decide things to the fullest extent of his ability.

Number three: Can Jimmy take advantage of any of the other alternatives to guardianship? Absolutely. Jimmy may have the capacity to execute powers of attorney for financial and healthcare decision-making. In videos three and four, we discussed advance planning and powers of attorney. Jimmy can appoint one or both of his parents as his agents. To do so, Jimmy must be able to understand what he is signing, what a power of attorney is, what it means to give someone else the authority to make his decisions and handle his money, and make a reasoned choice about who he wants as his agent. If Jimmy has the capacity to execute powers of attorney, he shouldn't need a guardianship or conservatorship. Jimmy should meet with a lawyer about doing powers of attorney to make sure he has the legal capacity to understand what he is signing.

If none of the alternatives work, Jimmy's parents may need to file a petition to become Jimmy's legal guardian. In Alabama, there is a special procedure for parents who are seeking guardianship of their adult child who has an intellectual disability. This involves filing a petition with the probate court in the county where Jimmy lives. The court will require a letter from Jimmy's physician stating Jimmy's condition, incapacity, and need for a guardian to make

decisions for him. The probate judge will appoint a lawyer – called a guardian ad litem – to represent Jimmy’s interests. The guardian ad litem should meet with Jimmy and speak to his parents and others familiar with his care and needs. Finally, the judge will have a hearing with Jimmy, Jimmy’s parents, their lawyer, and the guardian ad litem all present. If the judge is satisfied Jimmy is legally incapacitated and needs a guardian, the judge could appoint one of Jimmy’s parents as guardian, or both of them as co-guardians for Jimmy. In this case, co-guardians might be beneficial so either parent can act for Jimmy if needed.

The same procedure is available for Jimmy’s siblings. Let’s say Jimmy is now 59 years old and both of his parents have passed away. One of Jimmy’s sisters is taking care of Jimmy. She can file a petition in the county probate court to become Jimmy’s legal guardian. Let’s not forget that at any point, Jimmy may be able to execute powers of attorney and avoid an unnecessary guardianship.

Before we move on, let’s talk about Jimmy’s money. If Jimmy’s only source of income is SSI, and he has no other assets, he probably won’t need a court-appointed conservator. In that case, Jimmy’s parents or his sister could become his Social Security representative payee.

Next up, we’ll talk about another scenario in which guardianship or conservatorship may be needed – when an adult is being abused, neglected, or financially exploited.