

# The Transition Years<sup>1</sup>

by

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From a legal perspective, there are three very important things that happen in the lives of individuals with special needs between the ages of 18 and 21-22 (when they complete their publicly-supported public education).

1. The first, at age 18, results from their reaching the age of majority.
  - a. As children, decision-making about our lives is by- and-large practically and legally within the authority of our parents.
  - b. At age 18, all that parental authority ends. (Many parents acknowledge that, as a practical matter, it ends much earlier, especially with daughters.) In any case, it ends as a matter of law at age 18, and parents can no longer make legally-binding decisions on behalf of their children, whether the decision involves accepting or rejecting a course of medical treatment, applying for admission to a day or residential program, asking for records or challenging an agency decision.
  - c. We have an obvious problem with this approach
    - i. Decisions need to be made.
    - ii. As parent, I have no authority to act
    - iii. My daughter is not capable or making or communicating the decisions
  - d. Response
    - i. No decision

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- ii. Substitute decision
- iii. Guardianship is the process by which law determines when and how to put substitute decision-making in place.
  - 1. What circumstances appropriate
  - 2. How tailored
  - 3. Who is to be given authority
  - 4. Scope of authority
  - 5. Duration
  - 6. What standards apply to decision making
- e. Whether to invoke guardianship procedures requires dealing with an underlying conflict of two positive values or impulses
  - i. Protection
  - ii. Autonomy
- f. Mediating principles and procedures
- g. Avoid label trap
  - i. Functional not categorical basis to need for guardianship
  - ii. Capacity to make or communicate decisions
  - iii. How do you measure capacity?
    - 1. Clinical
    - 2. Emotional
    - 3. Circumstantial
    - 4. Experience with decision-making
  - iv. Presumption of capacity
  - v. Law's distrust of "good intent"
    - 1. Before there was a right to education, there was a right NOT to be excluded from regular class
    - 2. Before there was a right to treatment in mental hospitals, there was a right to refuse treatment
  - vi. Least restrictive alternative

- vii. Procedural protections
  - 1. Notice
  - 2. Opportunity to be heard
    - a. Hearing
    - b. Representation
  - 3. Special protections where authority is sought in certain legally sensitive areas, such as psychiatric placement, psychotropic medication, sterilization
- 2. The second big change that happens at age 18 involves changes in eligibility for government benefits
  - a. Some are available for the first time. The most important of these is childhood disability benefits. This is a Social Security program under which people who are first disabled in childhood may become eligible for disability benefits based on a parent's work record, if the parent is disabled, retired or deceased. Thus it is very important for people whose disability is such that they are not able to compile much if any significant work history of their own.
    - i. Eligibility usually comes later in the individual's life, for example, at the retirement of a parent
    - ii. Eligibility requires that the individual is continuously disabled between age 22 and date of initial eligibility, and that the individual be unmarried.
    - iii. Eligibility for childhood disability benefits (as well as disability benefits on one's own work record) results in automatic eligibility for Medicare as well (and thus also for prescription drug coverage) after 24 months of receipt of cash benefits.
  - b. With other programs, the financial eligibility rules change at age 18.
    - i. For example, SSI is available to disabled children from birth. However, until age 18, the income and assets of both parents are

usually taken into account in determining the child's eligibility. With one or both parents working and having even modest savings, the child is disqualified. However, at age 18, the parents' income and assets are no longer deemed to the child, whose eligibility is determined on the basis of his own typically very modest resources

- ii. MassHealth, as Medicaid is called in Massachusetts, is often of critical importance as a provider of medical, rehabilitation, and even residential services. Generally, the MassHealth eligibility of a child depends on the income and assets of his parents, as well as his own. (Significant exception - the Kaleigh-Mulligan program for children at home despite very severe needs.) As an adult, only one's own income and assets are counted. And for many persons under age and services under MassHealth, assets are disregarded altogether.
3. The third significant legal change that occurs during this period involves the end of the child's entitlements under special education law, and the start of her having to deal with the adult human services system. The age may be 21 or 22, depending on the state (or younger if the child obtains a high school diploma prior to the ceiling age).
    - a. The adult human services system is different from the special education system not only in name but also in kind. The most important agencies for children transitioning out of special education are the Department of Developmental Services (formerly the department of mental retardation), the Massachusetts Rehabilitation Commission and the Department of Mental Health.
      - i. Special education is an entitlement program, where eligibility is based on educational NEED. The schools cannot say "wait until next year" to meet a current need.

- ii. Adult services are not entitlements. Eligibility based not only on the need for services, but also on AVAILABILITY; said in another way, in the adult services system, you can be excluded regardless of need. You will now experience waiting lists.
- b. How to deal with this?
- i. Prepare early and often. Formal transition procedures are embedded into the education law of most states; depending on the state, this process can formally start as early as age 14.
  - ii. Build bridges to the agencies with which you will want to deal.
  - iii. Obtain what services you can from them - respite or case consultation.
  - iv. Join advocacy organizations, like ARC/Mass and COFAR, the Coalition for Families and Advocates. Go to their trainings and programs.
  - v. Make yourself part of the action.
  - vi. Obtain what services you can from them - respite or case consultation.
  - vii. Make yourself part of their budget projections.
  - viii. Stay informed.