



Special needs require special lawyers.

LESSONS IN TRANSITION: Planning for a Child Moving to Her Own Place in the Community

By Mary T. Schmitt Smith, CELA

Finding a suitable place in the community for an adult child with disabilities to live on her own is often a primary goal for both parent and child. Many parents find this goal difficult to achieve, knowing that a delay in the transition can reduce possibilities for placement. With a commitment to the goal, both parent and child can preview the child's future living arrangements. The process starts with identifying the child's needs and preferences. Then the parents establish a budget for the necessary supports to enable a successful transition for their child to live in a place of her own. They can make any necessary adjustments to their financial and estate plan, including the establishment of a special needs trust. This process presents opportunities for personal growth for both generations and enables both parents and child to move toward independence.

Impetus for the decision to move now: Denise and her daughter, Jean. Jean is a young woman of 37 years, diagnosed with developmental disabilities and mental illness. She attended Michigan public schools as a special education student until her eligibility for services ended after her 26th birthday. Classified as an "educable but mentally impaired" student, Jean is able to take care of her basic personal needs, and she can stay alone during the day. However, she takes medication to minimize her anxieties and needs some supervision and assistance. Jean is ambulatory, verbal, and able to navigate in a familiar area. She makes many of her own decisions and does not have a court-appointed guardian.

Changes in the economy, especially in the real estate market, prompted Denise to decide that it was now time for Jean to move out of the family home and into a place of her own. Denise, a widow of several decades and a retired schoolteacher, had already outlined her plans for Jean's future and put careful thought into her estate and financial planning to coordinate with those plans. She established a special needs trust for Jean with funds received from her husband's estate. The portfolio performed well under Denise's management and, although the total value was down over the past year, the trust still appears adequate to provide for Jean's benefit.

Also a mother of two sons, now in their 40's, Denise had already invested substan-

tially in her sons' educational efforts. She even helped one son purchase a house after his divorce. Even so, a majority of her planning focused on assuring Jean's future needs would be met.

Denise and her daughter had lived together for all of Jean's 37 years, and Denise was wearying of Jean's repeated requests to have her "own place." Jean did not understand why she couldn't live independently and wanted the opportunity to try. After all, she knew her brothers already had made that move long ago.

Increasingly, Denise questioned her own judgment and whether her hesitation to consider Jean's request was because of her own overly protective concerns. Having celebrated 75 birthdays this year, Denise wasn't getting any younger and, while feeling fully capable, she wondered inside how much longer she would continue at this level. More than anything, Denise wanted Jean to have what she needed: a place of her own. Denise also wanted the opportunity to preview how her careful planning would work once Jean moved out. Then, if changes were needed (even expected), Denise was comfortable that she would be able to address those while she was fully able to adapt her plan to meet Jean's needs.

Realizing the single largest impediment was in her own heart, Denise knew the transition was inevitable. She needed to embrace the opportunity and no longer defer Jean's requests by maintaining the status quo. After finally coming to this conclusion, Denise was propelled into action: now was time for Jean to transition to a place of her own. Both women were more than ready to move ahead.

The final factor driving Denise forward with the venture was her desire to show her sons that Jean's long-deferred dream was possible. By showing her sons how this transition could be accomplished successfully, as successor trustees they would be able to continue managing and moni-

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toring Jean's living arrangements. They would also have the benefit of Denise's accumulated knowledge and added confidence to administer the special needs trust for Jean's benefit.

Jean's Individual and Personal Needs. Jean's transition plan encompassed the usual range of issues encountered when any young adult leaves the family home and sets up a household. They included acquiring furniture (especially for her room), supplies, décor, and window treatments, as well as any cleaning and/or painting. Jean's dual diagnoses of developmental disabilities and psychiatric/mental illness also required considering other factors above and beyond her basic food, clothing and shelter needs. In addition to family resources, Denise needed to determine if any community resources were available from Medicaid or

ularly stable on her feet, it would be best if steps and stairwells were minimal. Pets, while welcome, would not be included, at least not until after she had adjusted to the initial move.

Budgeting. Jean's new household needs a budget to include food, utilities, taxes and maintenance as well as her personal needs. In addition to earnings from her part-time job, other sources to pay for basic food and shelter costs include Social Security Disability Benefits (SSDI), based on her mother's work record. Fortunately, Jean has been a careful spender and was able to save some of her earnings to buy clothes and other select purchases. In the future, Jean could consider inviting a roommate to contribute toward household expenses.

Jean's governmental benefits: Jean has never been able to work. However,

a Medicaid "spend-down" plan.) Since Denise is also receiving Social Security retirement benefits on her work record, she knows that after her death, Jean's monthly benefit will increase under current law, because she will then be the only beneficiary drawing on her mother's earnings record.

Health insurance: A retired public school teacher, Denise enjoyed an enviable healthcare package of benefits from her former employer. So long as Jean was living with her mother, Jean would be considered a dependent. While that provided an income tax benefit to Denise, even more valuable was Jean's eligibility for a generous supplemental health insurance (Medigap) policy, including prescription drug coverage. Once Jean moved out, she could no longer be claimed as a dependent on Denise's income tax return, and Jean's eligibility for the paid-for Medigap or drug coverage would end. However, Denise knew this would happen ultimately upon her death. She was ready to take the steps to get Jean enrolled in a new plan and obtain a policy of her own to supplement her Medicare insurance.

Coordinating the budget plan with Jean's existing special needs trust: Once Jean's basic needs were identified and budgeted for, then distributions from the special needs trust could provide for her supplemental needs. The trust gave the trustees full discretion to decide how the funds would be used for Jean's benefit and best interest. In addition, the trust directed the trustees to evaluate Jean annually and address the following topics:

- Her physical condition and medical needs;
- Educational, residential and vocational opportunities;
- Recreational, leisure and social needs and opportunities;
- Appropriateness of existing program services;
- Laws and administrative practices relating to various governmental financial assistance and benefit programs, because

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its waiver programs to help Jean with transportation, housing costs, and supervision from the local community mental health agencies.

Housing. *Location:* Ideally, Jean's new home would be situated close to her part-time job and other places familiar to her for shopping, library, recreation, and visiting with her friends. One important factor was access to transportation services so Jean could get to doctor appointments, maintain contact with her pharmacy and, if needed, a hospital. Ideally, it should be located within a short distance of one or both of her brothers' residences.

Interior: Mobility within the home would be key for Jean. Because she is not partic-

because her disability arose at birth and was documented before she reached age 22, she was able to qualify for SSDI benefits based on her retired mother's work record. Jean's monthly benefit is almost \$1,000, and she also has Medicare coverage to help pay for her medical needs. This set of benefits is not means-tested, so the special needs trust could pay for her shelter-related costs. (If Jean were receiving means-tested benefits such as Supplemental Security Income or Medicaid, the shelter expenses paid by the special needs trust would reduce the amount of her monthly SSI benefit payment. To be eligible for Medicaid benefits, Jean would spend a portion of her monthly income on medical expenses, known as

Jean may not have a reasonable chance of earning sufficient income to support herself, and it is essential these benefits be secured; and

- Legal rights, including treatment in accordance with her needs, a minimum or fair wage for work performed, and the right to vote and to marry.

The trust provides that the annual evaluation should reflect individual contacts with Jean, her social worker or support coordinator, her “circle of friends” and other individuals who are in regular contact with her, including any service providers. A copy of the report may be submitted to the guardian, if one is appointed, or to any advocate(s) that Jean may request.

With the information from the annual evaluation, the trustees will be equipped to prepare an annual budget to address Jean’s primary and supplemental needs. The budget proposes spending all of the annual income for her benefit. This approach assures the trust income is taxed at the beneficiary’s (Jean’s) individual rate, which typically results in paying the least amount of tax.

The search for housing. Denise and Jean set about identifying suitable housing for Jean. Fortunately, they started working with a realtor who was willing to spend the time to find the “right place” that worked for Jean. With the local economy paralleling the plight of the automotive industry, the market for condominiums in the area had never been more attractive from a buyer’s point of view.

The search ultimately located a two-bedroom, two-bath ranch condo located near the condo complex where one of Jean’s brothers lived, and the FHA-required inspection revealed few issues. Since new kitchen appliances were needed, that gave Jean the opportunity to make her own selection from more energy efficient models, reducing her utility expenses.

Denise considered whether the purchase should be made by Jean’s special needs trust or from Denise’s own revoca-

ble trust fund. Denise determined that she would purchase the condo and hold its title in her own trust agreement. Then Denise updated the terms of her own revocable trust agreement to specify that title to the condo (or any replacement residence) for Jean would pass to a special needs trust established for her under that trust agreement. With this approach, the equity would be protected and Jean would not be vulnerable to possible financial exploitation by another and risk loss of her home.

With her new home selected, to be titled in Denise’s trust, and a budget developed, Jean was ready to pack her belongings and begin fulfilling her dream to live on her own. With the support of family and the special needs trust established to provide for Jean’s long-term benefit, mother and daughter are now each looking forward to independence. •

Mary T. Schmitt Smith is Michigan’s first Certified Elder Law Attorney. Mother of three, she has two children with disabilities. Mary served twelve years on the Board of Directors of The ARC of Oakland County, Inc., the nation’s sixth largest ARC. She was elected to the Board of Directors of National Academy of Elder Law Attorneys (NAELA), and was honored as a Fellow of the Academy in 2003. In recognition of her community service for individuals with disabilities, Mary received the national Theresa Foundation Award. Inspired by that award, she established the Theresa Law Center in May 2005 to continue a twenty-five year tradition of legal advocacy, advising clients about estate and trust administration, governmental benefits, tax and probate matters, emphasizing on drafting and administering special needs trusts. To learn more about Mary and her practice, visit www.theresalaw.com. Mary is a charter member of the Special Needs Alliance, a national non-profit organization committed to help individuals with disabilities and their families. Contact information for a member in your State can be obtained by calling 877-572-5472 or by visiting www.specialneedsalliance.com

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