



**Social
&
Recreational**

**Financial
& Legal
Planning**

ZACK



**Health
&
Wellness**

**Vocational
+ / or
Day
Program**

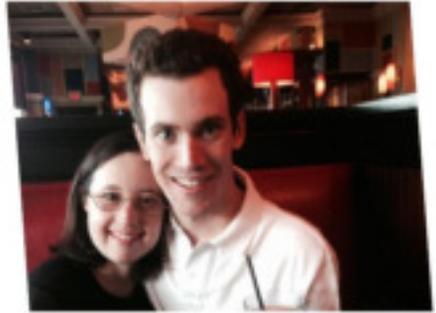
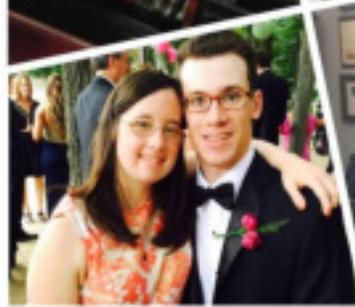
**Caregiving
&
Support**

**Residential
&
Transportation**

Life Is Good

PLANNING A LIFE

LIFE IS GOOD

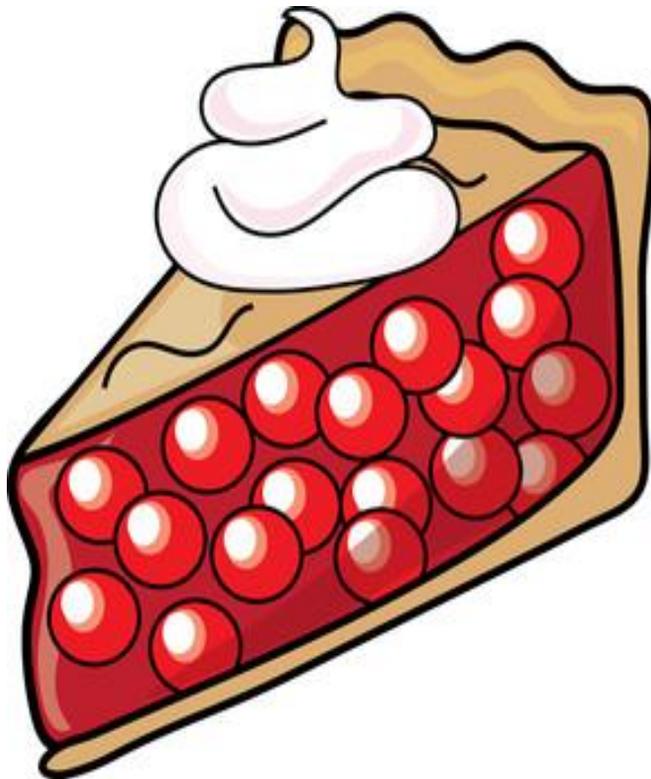


WINSTON

ZACK & MOLLY

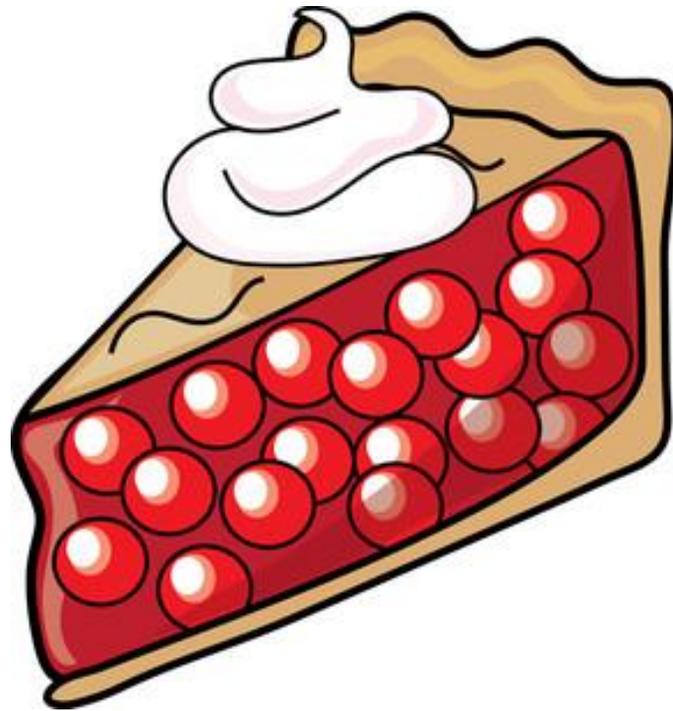


SLICE OF PIE



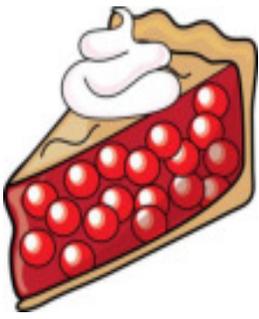
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A SLICE OF PIE



PLAN-INITIATE-EVOLVE





Legal & Financial

Professional estate planning/special needs attorney

Create families' estate plan and integrate with Special Needs Trust, and whatever other planning strategies would be beneficial based on family resources and circumstances.

Financial Plan

Create a comprehensive plan designed to identify the supplemental needs for your child while the parents are alive, and to determine what changes, if any, may need to be considered so parents can try to achieve all their goals, including their own retirement, educational goals for family members and whatever else the parents want to address. Also, identify how much capital will need to be available for your child after the last of the parents are no longer the primary means of support. This includes maximizing all available benefits that can provide the evolving/changing support your child may benefit from.

Seek out a qualified financial planner who is experienced with special needs planning to assist you in putting a plan in place.



CAREGIVING

Many of our children require some level of support irrespective of where they live. When they transition from school, it is important that you identify what that looks like. Is it a program that provides the necessary support? Is it a full-time live-in caregiver? Is it just an appropriate roommate? Is it a competent adult checking in periodically?

Resources:

- Private Pay
- DDS/ID: (Residential/ Priority 1). Can be traditional group home, shared living, self-directed model.
- DDS/Autism: Can be support staff necessary for client to be successfully integrated into the community.
- AFC/GAFC (MassHealth/Medicaid)

Adult Family Care: Level 1 (\$9,000) or Level 2 (\$ 18,000).

Group Adult Family Care – more than three:

Benefits generally average about \$ 600/mth.

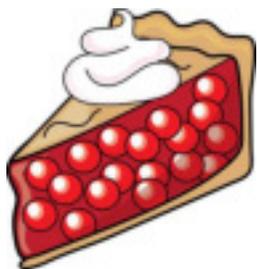
Must be clinically eligible.

Must have needs (cueing, reminding, physical assistance) with one, or more ADL's

(bathing, dressing, eating, incontinence, transferring and ambulation). For Level 1 need only one ADL,

for Level 2 need three ADL's or two ADL's and behavioral issue.

- Parents/Family



Vocational &/or Day Program

What is your child going to do during the day? This could be the most important part of the planning process. Most of our children are capable to work, and if they want to work, they should. You, your child, and the school, must emphasize this so that your child is ready, and able, to pursue their vocational goals.

“Post 22” resources:

DDS – Priority funding for “day supports” (supported employment, community-based day supports, ...). Can include vocational training, job placement and job support. Must be domiciled in MA. This should start at 18 by getting Mass ID card.

Mass Rehabilitation Commission (MRC - the Massachusetts vocational rehabilitation agency).

Vocational Training Programs (ICI, JVS, Work, Inc., ...)

This aspect of our student’s lives can be crucial for a successful residential transition. If your student is happy and fulfilled at their job (whether paid or volunteer), it often results in a tremendous amount of self-esteem which can propel them to gain confidence with all the other aspects of their lives. It may be the most important thing that advances their independent living skills.

Parents can enhance the opportunity for success by starting early (age 18 or 19) to identify who/where/how they are going to achieve this goal.

Gather a working knowledge of the adult provider agencies in your area, and learn what they can, and cannot do, for your student. Your plan needs to be in place well in advance of your student leaving the Riverview program.



Residential & Transportation

Transportation:

Independent travel unlocks the obstacles from our children accessing the community and everything it has to offer.

Consider where, and how, your children are going to access their transportation if they are not capable to obtain a driver's license.

It can be a combination of public transportation, paratransit systems for people with disabilities, ride share services, walking, or private services.

It can get very expensive paying for Uber services and private transportation. Public transportation is by far the least expensive, and also enables our students to get where they need to go, when they need to get there.

Post 22 resources:

The RIDE, or other regional paratransit systems.

Commuter rail, subway, or buses. (discounted fares).

UBER or LYFT (through the MBTA The Ride Pilot Program).

Travel Training (Innovative Paradigms/MBTA – free personalized travel training for MBTA services/bus and subway system).

Residential:

Group Living/Shared Living/Apartment/Condo with, or without, roommate(s)/ Family home.

Post 22 resources:

DDS - Priority 1 Residential

Private programs (Specialized Housing, Inc./ LIFE / Agency provided housing / Halyard / N.E. Village ...).

Section 8 voucher (rental subsidy).



HEALTH & WELLNESS

- Generally speaking, it is best to keep them on your private insurance as long as you can (at least to 26, and often beyond). This will allow you to possibly participate in the Premium Assistance program (MassHealth member must live with insurance holder).
- **Medicaid** (MassHealth). Either eligible by being SSI eligible (at age 18), or a separate application (if not an SSI recipient). Rules are different as to how the Medicaid status is preserved. If SSI, can only compromise by earning over the state threshold (earned income in excess of about \$ 43K).
- **Medicare**. Long term health insurance. Our kids generally are eligible for Medicare because they become SSDI recipients. They can get SSDI eligibility either on their own work record (quarters of credits - \$ 1,410 per quarter), or on parents account if DAC/CDB (disabled adult child/childhood disability benefit). DAC status can be compromised if earning SGA. There are two timeframes where work can affect eligibility for DAC. First, in order to be eligible for DAC, a child cannot have participated in Substantial Gainful Activity (SGA) after the onset of disability but prior to initially qualifying for CDB. In 2020, an individual earning more than \$1,280.00 per month is presumed to be engaged in SGA and therefore may lose their DAC status. If the CDB benefit has not started, they will be considered DAC's so long as they have not earned over SGA before being eligible for their DAC benefit. Once they are receiving DAC benefits, that can earn over SGA but are subject to the Trial Work Period (\$ 910/mth for nine months), EPE- Extended Period of Eligibility-36 months after TWP. After EPA ends, and if still SGA, cash benefits will stop and be considered "terminated". Benefits can be reinstated (EXR), if reinstated within five years from when cash benefits ended. You can always reapply, but there is no guarantee you will be eligible for these benefits.



- SSDI beneficiaries keep their Medicare coverage up to 93 months (about 7 ½ yrs) after the end of TWP if their SSDI status is terminated.
- Counseling (licensed psychologist) can be available through MassHealth/Medicaid (we used Harbour Counseling from SNARC).
- Behavioral Therapist can be available through AFC if provider agency offers. In our case, Advocates, Inc. (our AFC provider) offers this service.
- Consider transitioning from pediatrician to adult physician (we discovered Zack has hypothyroidism as a result).
- Dental Care. Can receive limited services from Mass Health. However, if you are a DDS client, the services are more comprehensive. Zack goes to a dentist two blocks from his home who accepts Mass Health and she does his cleanings (four times per year – not fully covered, cavities, ...) It is very difficult to find a dentist who accepts Mass Health. Tufts runs a program that provides dental care for DDS clients with Mass Health.



SOCIAL & RECREATIONAL

- Special Olympics (Brookline Park & Rec)
- Jewish Big Brothers & Sisters (MAGIC – non-disabled mentor)
- Partners for Youth with Disabilities (to age 25ish).
- DCR (Dept. of Conservation & Recreation): Community rowing and sailing on the Charles River.
- Boston Sports Club (physical fitness two times per week).
- Forever Young (dinner every two weeks).
- On the Town (monthly Friday night event).
- Girlfriend (Molly – dating for twelve years). Molly moved into the apartment on 10/1/18 & now they are engaged.
- Volunteer (Zack is working with MAB to be placed with a person who has sight impairments that needs some assistance).
- Friends (Red Sox, sporting events, rowing, movies, pizza)
- Parents, brother, relatives.