Challenges to Transitioning Gracefully To Adult Services for Individuals with Autism and Other Developmental Disabilities: Master Thesis

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**Method**

A search of information on the transition process to adult services for individuals

Who were about to turn the age of turning twenty-two and had been diagnosed with

autism and other developmental disabilities was conducted. Several peer review articles

were chosen. These articles were based on the transition information, Transition

Plan, and information on Individual with Developmental Disabilities Act (IDEA).

Due to a lack of research which identifies the components to transitioning a further

more comprehensive search of the Webb yielded information about 688, guides to

transitioning and media articles about how problematic the transition to adult services

is.

**Participants and Settings:**

The manual is for Individuals with autism spectrum disorder and other

developmental disabilities age 14-22, their parents, educators, professionals and adult

service providers in the State of Massachusetts.

**Manual Sections**:

Introduction

**Section 1:** What is transition and transition planning?

Legal information that includes IDEA, Rehabilitation ACT; including information when a child ages into adult hood, obtaining a state ID, registering to vote, selected services, adult medicine and etc.

Eligibility for SSI (then include work expense initiatives)

**Section 2:** What are the areas that IEP and Transition planning should cover?

Employment, post secondary education, independent living, and community integration

**Section 3:** What are the adult services and how are they funded

\*\* entering adult services is the end of entitlement and therefore no service is guarantee

Residential options (group home, Individual service option, foster care, independent and etc), day program options (sheltered, community based, employment, day habilitation) Transportation, and post secondary school

Medicaid (federal) funded programs- what is needed for them (health insurance)

**Section 4:** When should the individual and parents begin the process?

State agency is first contact at age 18- turning 22 coordinator, eligibility for adult services and etc, Information provided by 22coordinator (service providers). Development of Individual transition plan (identified services for adult services)

Touring various adult providers; documents required for adult services, adult providers attending meetings, recommended transition plan (start date, visits, type of program, transportation and etc).

**Section 5**

Conclusion

**Social Validity**

Transition to adult services is a major milestone and the planning for this

transition has social importance to the person entering adult life and adult services.

This process needs to be implemented early to have a positive experience and

outcome. There must be an effective plan in place in order to reduce the stress the

transition has on the individual and parents. Therefore it becomes important to know

and understand the process from leaving educational services to services that are

provided for adults from the state. Starting the process early allows for the time

necessary to provide the appropriate services. Gathering information from parents,

educators, state agency coordinators and adult providers was part of this process in

developing a manual to implement best practice. In order for the manual to have value

it must be reviewed by adult providers, state coordinators, parents and educators.

**Section 1:**

**A: Introduction**

There are several challenges to a smooth transition from educational services to

adult services for individuals with autism spectrum disorder and other developmental

disabilities. For the student who is transitioning they are leaving an environment that

provided structure, consistency, familiarity and a wide range of entitled services. For

the parents’ there is a lack of familiarity with the state agency and the lack of

information of the variety of services that are offered to adults. Parents and the

students are left on their own to navigate the different services as the state agency did

not provide the necessary guidance. Parents have not yet prepared themselves to the

fact that their son or daughter are now an adult and are no longer considered children.

Sometimes services are interrupted because the planning for the transition

occurred late, residential home is not yet developed and lack of openings in residential

and day placement, therefore the person remains at home. There is lack of funds to

provide the necessary supports the student will need to function in daily (Holmes, 2007).

Many adult services are not qualified to provide services to individuals with ASD or

individuals who exhibit challenging behaviors. These issues all work against a smooth

transition (Gerhardt & Lainer, 2011). The transition process needs to change and

parents should be provided the information to ensure this occurs as the fiscal resources

to support this are available under The Individuals with Disabilities Education Act (IDEA)

(Gerhardt et al., 2011).

Currently adult outcomes are demonstrating that the transition plans for

individuals with ASD are not in compliance with IDEA. Individuals are not equipped with

the skills necessary to function in adult life as they were not provided with employment,

community participation and residential independent living (Gerhardt et al., 2011).

Although there are several residential options only a small percentage live alone and

some actually live in long-stay hospitals or institutions. The majority continue to live at

home (Hendricks & Wehman 2009). Freidman (2013), reports that a national study

concluded after two-years of transitioning from educational services, more than half of

young adults with ASD did not participate in either employment or post secondary

education. The majority of individuals with ASD continue to experience unemployment,

change jobs frequently and are underpaid (Hendricks et al., 2009). Lastly community

involvement is lacking because leisure activities are isolated and typically involve

video games (Hendricks et al., 2009). Only 30% report having at least one friend but

many report they want to have friends, intimate relationships and more engaging social

activities(Hendricks et al., 2009).

Transition is in the fore front with students with disabilities who are turning twenty

two. Since the 1990’s there has been an increase of person’s being diagnosed with

ASD and this generation are now exiting out of entitled services. Adult services are

very different than what was received in the school system. There is no guarantee that

the individual will receive services for day programs, residential services,

adult education and employment as there is no entitlement after the student turns

twenty-two. Since the age of fourteen students have been planning their post school

goals. IDEA requires transition planning to begin at the age of fourteen (Promoting

Effective Parent Involvement in Secondary Education and Transition, Parent

Brief 2002). The Individual Education Plan (IEP) must have a statement of the student’s

transition services that document the student’s post school goals which represent the

student’s needs and preferences (Promoting Effective Parent Involvement in Secondary

Education and Transition, Parent Brief July 2002).

By the age of sixteen the IEP is required to have a statement of the needed

transition services. It must also contain a statement of interagency responsibilities, if

appropriate. The statement must outline the coordinated procedures with measurable

outcomes that will advance the student from school to post school activities (Promoting

Effective Parent Involvement in Secondary Education and Transition, Parent Brief July

2002).

During the last two years of school, at the age of nineteen, the student

should be referred to appropriate outside agencies. These agencies should be

working with the school department and planning for the services the student will

utilize after turning twenty –two. The Department of Education has a legal

obligation to involve outside agencies in the transition process and the state

agency must develop an individual transition plan (ITP) with the IEP team. The

ITP documents what the individual will require for adult services and it should contain

what agencies will be responsible in providing them. However there is no

guarantee that these services will be provided as there is no entitlement.

Transitioning planning is a long process and the student, family and educators

have been working on preparing the student for post school goals that may involve adult

education, employment, medical, community involvement, independent living or

residential services. The main challenge is not the skill level the student has but the

process to navigate the adult services, if required (Hendricks et al., 2009). There has

been multitude of research done in the transition planning for post school outcomes in

the education research. However there is limited research concerning an individual’s

transition into adult programs and the process itself (Hendricks et al., 2009). There is

some broad guidelines on what to do, but not a step by step guide of how a person or a

parent of an individual should transition to adult services.

**Recommendations for Transition to adult services**

For transition to adult services to be successful parents and students need to

know the components associated with the process to have a successful experience and

outcome. Becoming knowledgeable about the legal requirements to qualify for services

from agencies and organizations is a necessity. Begin early to understand what adult

life may look like. The process of gathering information about adult services and the

focus needs to be in the same direction of when transition planning started. Because

IDEA ensures that transition planning occurs; the focus should be on what are the adult

services; community day base supports, employment, day-habilitation, residential,

continuing education and then how do they vary in supports and programming.

Information on how they funded including having foresight about transportation.

The purpose of this manual is to be a resource in transitioning to adult services.

It will define transition; identify the problems associated with transition planning, when

transition planning begins for post school activities, strategies that might assist in

receiving services and provide the components to transition to adult services easily and

effectively. The manual will highlight the different types/programs that are offered to

adults (Day-Habilitation, employment, community based, and the various residential

options).Information about Rehabilitation Services Administration (RSA), eligibility for

Medicaid, Social Security Income (SSI) or Supplemental Social Security Disability

Income (SSDI). It will be a step by step process that outlines and guides a parent or

student through the process.

**B: What is transition and transition planning?**

Transition is something that we all experience beginning at birth. It

encompasses all aspects of one’s milestones in childhood, adolescents and adulthood.

There are enormous amount of transitions taking place. They range from being

dependent on our parents to living on our own, graduating from high school, going to

college, gaining various employments, having relationships, day to day activities,

marriage, etc. For a majority of us we identify who we are based on the environment

and supports we have. For individuals with autism and other developmental disabilities

transition can be more problematic as change in one surroundings can be and is

disruptive. Therefore planning for post school services is necessary and should be a

gradual process. The plan should provide opportunity for growth and outcomes that will

benefit ones future in adult life. This planning is often referred to as Transition

Planning/Services. The federal law indicates that transition services must be a

coordinated set of activities for a student which has movement and is a results oriented

process. It is critical for the transition planning to begin by age 14, because as one

grows older one needs to have the necessary skills to adjust to adult life. Transition

planning involves planning for what will happen after high school; employment, adult

services, independent living, post secondary education and community participation.

**C. IDEA 2004**

Federal law states that transition planning begins at the age of 16. Individuals

with Disabilities Education Improvement Act (IDEA 2004) protects student until the age

of 21. IDEA established that students with disabilities have the right to free, appropriate

public education (FAPE). State and local school systems receive federal funding to

develop and provide special education services. An Individual Education Plan (IEP) is

developed based on the individual needs and identifies the services and supports

needed to educate and prepare a student for various post school activities in the least

restrictive environment.

The transition plan is incorporated into the IEP and the student needs to be

invited to the meeting and take part in his/her plan. The plan needs to be based on the

student’s needs and capabilities. It identifies the student’s interest and preferences.

The overall objective to this plan is to help develop the student’s competencies to

function in adult life. The transition plan should have realistic time frames and

expectations. In order for the transition plan to be successful there must be a support

system that facilitates the opportunities for development in either or all post school

activities. These activities are the following; post secondary education,

vocational/employment opportunities, independent living and community participation.

As a parent one must understand a person is legally considered an adult at the

age of eighteen and planning for the future is necessary. As one becomes an adult one

should have had the necessary assessments and opportunity to increase one’s ability to

function in ones environment. The transition to adult life is planning for future needs

including health care, employment, education, and independent living. If your son or

daughter requires guardianship you should have guardianship completed by the age of

18. If you do not obtain guardianship, the educational system legally is required to

develop the IEP based on what the student wants and desires as he or she is

considered an adult and legally competent to make decisions.

**D. Guardianship**

When your daughter or son turns 18 they are presumed competent disability or

no disability. This means as an adult one is able to make decision about ones own

education, health care, finances, and various other areas in one’s life. It also means

parents cannot legally make decisions for their children even if they are still living with

them. This can be very shocking to parents especially in the areas of education (IEP)

and medical issues. As a parent, one needs to decide to apply for guardianship or not.

Guardianship is a legal process. In the State of Massachusetts, petitions for

guardianship can be submitted when the person turns 18. When filing the petition there

must be a clinical team report for a person with an intellectual disability. This report is

completed and signed within 180 days of filing the petition by three professionals:

registered physician, licensed psychologist and licensed social worker. If your child is

receiving special education, the school system should have a team that includes a

licensed psychologist that could complete the clinical team report.

It can also be helpful to consult your child’s primary care physician in order to see

what resources he or she may be able to access. Another resource parents have is

your child’s pediatrician. Lastly the Department of Developmental Services can aid in

the process as the state has access to professionals.

There are several different types of guardianship: Legal guardian is able to make

decisions. A Limited Guardianship allows for the individual to continue making some

decision in his/her life and identifies what area the child needs decision making for such

as medical care. Another type is Guardian of the Estate or a conservatorship, which is

responsible for the finances of the person. A Representative Payee is another person

who makes decision for an individual. This is for someone who receives a check from

social security. A Temporary Guardian can be obtained in emergency situation and is

only short term. There are various other guardianships that you may want to look into (

health care proxies, person who can speak with Medicaid, advocate to help with making

decisions with the school or the various state agencies). In most cases a person can

have co-guardians but there are complications with this as well because both guardians

need to sign all documents. If as a parent you know that your child is unable to make

decisions for medical treatment one should considered guardianship. If your child is on

antipsychotic medication, he/she requires a Rogers Monitor.

**E. Chapter 688**

In the State of Massachusetts, Chapter 688 is a referral process that identifies

the needs and supports that an adult with disabilities will need. This process is

necessary as it will identify the needed funds necessary to support adults when they

turn 22. Therefore parents/guardians need to apply for eligibility for adult services

because entitlements for special education end when the student turns 22. Chapter 688

is a two year planning process that is coordinated and requires a transition plan which is

part of the IEP. The student must be referred 2 years prior to graduating or turning 22.

School systems refer the students to be eligible for adult services. It is a 2 year process

because it provides the time necessary to determine eligibility for adult services and for

the various state agencies to forecast a budget, which is then given to the state

legislation each year. If filing for eligibility is late it will effect funding for services.

Parents and guardians need to have the various documents for applying for

eligibility. Therefore a portfolio with the following documents will ease the process of

applying for eligibility.

**Medical history**: doctor reports, list of medications, diagnosis, hospital admissions, hearing and vision assessments, etc. Behavior assessments, evaluation on development, counseling record, testing (psychological, IQ tests, Vineland ANA, ABAS, etc and early intervention)

**Education History:** IEP, 3 year evaluation, assessments and progress reports

**Legal documents**: guardianship, Rogers guardian if over the age of 18, social security card, birth certificate and health insurance card (private, Medicaid, Medicare (copies of the front and back of card)

During this time, parents should also obtain a State picture identification or drivers license.

**F. MASSCAP**

The State of Massachusetts also completes the MASSCAP, which is the

Massachusetts Comprehensive Assessment Profile. There are three parts to it; the first

is the ICAP (Inventory of Client and Agency Planning), the second part is the CCA

(Consumer and Caregiver Assessment) and the third part is the Professional Judgment.

The ICAP is the assessment of the client’s adaptive functioning, level of support needed

and how much supervision is required. It is a standardized validated assessment tool,

which is completed by an Eligibility Specialist and conducted when applying for eligibility

services. The CCA evaluates the clinical functioning of the individual, the demographics

of the caregivers and the capabilities of the caregivers. The professional Judgment is

formed based on the ICAP, CCA, direct observation and interviews with the family by a

trained and experience professional. The overall objective of this profile is to inform the

Department or Developmental Services (DDS) the student’s abilities and needs and

determine what services the department can fund and at the same time evaluate the

needs of the student’s family. The MASSCAP determines if the individual meets the

qualifications for the particular services requested, determines who needs intensive

services and prioritizes the individual for the requested services. The ICAP measures

the amount of supervision needed. If the scores are below 40, the person is eligible

for residential supports with 24 hour supervision. If scores are 40-70, he/she the

individual may receive funds for residential services. If the individual scores above 70

on the ICAP, he/she does not meet the qualifications for services.

There are three levels of prioritizing for services; the first is priority one, which

indicates that the supports are required in order to protect the health and safety of the

individual and others. The second is priority 2, which determines what support

are necessary to meet the needs of the individual. DDS works with the individual and

family in determining which services are needed while waiting for prioritized services.

When assigned as a priority 2 the person or guardian needs to be willing to accept the

services when offered. The third is no priority assigned. This means that the person

does not qualify for services or the individual does not want services as this time.

Priority levels can change based on clinical changes of the individuals and the

caregivers ability to meet the support needs of the individual.

**G. Vocational Rehabilitation Act section 504 and American Disability Act**

The Vocational Rehabilitation Act section 504 and American Disability Act are

civil rights laws. That were developed to protect individuals with disabilities. The laws

are to ensure that an individual receives equal access and services in school, for

employment and public accommodations and not be discrimination because of

disability. There must be appropriate services and supports to meet the needs of the

individuals. The school systems receive Federal funds therefore Section 504 applies as

school systems are institutions. ADA does not involve Federal funds, however it widens

the protection to state and local government and public services. An individual must

have a physical or mental impairment that limits a person and there needs to be a

history of this impairment that impacts at a major area in one’s life.

**H. Social Security, registering to vote, selected services, adult medicines**

**Social Security (SSI or SSDI)**

To receive SSI an individual needs to meet certain requirements. Children under

the age of 18 can qualify for SSI if the disability meets social security definition and if

the income in combination with others in the household meets the eligibility limits. At

the age of 18 individuals with disability can apply for SSI benefits. An individual needs

to meet SSI strict definition of a disability, which is a person is unable to do any

substantial work because of his/her medical conditions and the medical condition has

lasted or will last at least one year or the medical condition will result in that persons

death. When your child turns 18, the income or resources of the family is no longer

taken into account when determining eligibility. The benefits are paid by either the

Social Security Disability Insurance (SSDI) or Supplemental Security

Income (SSI). Social Security will assess if a person working is at a substantial gainful

activity (SGA). If earning over $1,000 per month the person will not be eligible for social

security disability payments.

Social security evaluates how severe the intellectual disability is by using a scale

from A-D. When one requires supports in most areas and the IQ score cannot be

determine the individual meets the criteria for A. For criteria to be met for B a person’s

IQ is below 59. When a person has an IQ between 60-70 and has a mental, physical

impairment meet or has an intellectual disability sever enough meets the C criteria.

As employment opportunities open SSI has develop a program to provide

additional funding to support individuals with autism and other intellectual disabilities. It

is a work incentive program and is referred as IRWE (Impairment Related Work

Expenses). It allows for partial cost for job coaching, travel and job modifications to be

deducted from the individuals earned income while maintaining the individuals SSI

payment.

**Medicaid**

Medicaid is a federal program that allows for medical coverage. It is additional to

private insurance and is used after the private insurance. Once a person obtains this

insurance it needs to be completed annually and on time. Children who have a

diagnosis of intellectual disabilities or autism may require behavioral, speech,

physical and occupational therapies which Medicaid has no co-pays r deductibles.

Typically if a person is eligible for SSI, he/she will automatically be enrolled in Medicaid.

Medicaid also has waivers which are Home and Community-Based Services (HCBS).

It allows for person with disabilities to remain at or residential services while

receiving medical and non-medical services. It provides long term care to individuals

who meet the eligibility requirements.

When your son or daughter turns 18, he/she has typically out grown his/her

pediatrician. However, there are pediatricians that continue to provide health care until

21 and some continue into adulthood. However, health care is different from being a

child than health care as an adult. Once the persons turn 18 he/she can be referred to

an adult primary care physician (PCP). It is a difficult process as one needs to know

who specializes in the needs that your child has with a particular diagnosis or

conditions. The transition will be smoother if you begin to look for PCP who accept

Medicaid and are knowledgeable in your child’s diagnosis. Began looking when your

child turns 18 and gradually fade from the pediatrician to the PCP as you child is

comfortable with the new doctor and routine.

**Selected Services**

It is required by law that a male who is a United State citizens must register

within 30 days of his 18th birthday. Documentation of a person’s disability is required

when registering and it must identify why the person is not able to serve (diagnosis,

hospitalizations, institutionalized, etc). A person can assist the person with the disability

in registering. The person must register and the government will determine if the

individual between the ages of 18-25 is fit for duty.

**Registering to Vote**

In order to vote in Massachusetts one must be a resident, be 18 years or older

and a United States Citizen. It is a civic duty. There are laws that protect the individual

with a disability the right to vote (ADA, the National Voter Registration of 1993 and Help

American Vote Act of 2002).

**Section 2**

1. **What Areas Does the IEP and Transition Plan Cover**

As already indicated at the age of 14, the IEP must have a documented

statement of transition services. When the student reaches the age of 16 the IEP must

have a statement of the required transition services. This addresses who will be

responsible in meeting the transition services and outlines the strategies that will help

obtain what a person will need as he/she enters adult life.

The IEP and Transition plan is one plan based on the student’s needs and

capabilities. This plan will facilitate how to enhance a student’s academic and functional

capacities. It will highlight a student’s preferences for employment, education (college

or adult education, living arrangements, adult services and community involvement. It

includes instruction (where it will take place, involves academics, living and vocational

skills) related services (occupational and physical therapy, transportation, speech,

behavioral and other services that benefits the individuals), community experiences (

activities outside of school), employment (evaluating career opportunities, vocational

training, experience employment, how to interview, resume development etc), daily

living skills ( hygiene, cooking, laundry, cleaning, searching for apartments, budgeting

skills, voting, socializing with others) and functional vocational evaluation (assessment

on preferences for employment). There will be steps on how to meet the goals

developed, what strategies will be implemented, timelines in achieving the goals and

who is responsible in supporting the individual goals. If it is decided by the entire IEP

that an area is not a need there must be a statement as to why.

The planning process for transition should be a vehicle for the student and

his/her parents to meet with an agent from adult services. Adult services will aid in

transitioning to adult services. If there are identified outside agencies that do not

provide transition services that have been identify in the IEP, there must be another

IEP meeting that will develop alternative strategies that will meet the objectives. IDEA

ensures that the adult agency is responsible to either provide or pay for the transition

services. who meet the adult agency’s eligibility requirements.

1. **The Transition/IEP Team**

The student should be involved as much as possible. Parents and family members

are important contributing members. Transition planning has long-term goals and the

student and student’s family are the ones who are going to be long term advocates

when the student enters adult services. The professionals (teachers, therapists,

administrators and other outside agencies) are also valued members. Each member

has a role in implementing the plan, overseeing the supports, collecting the data and

writing assessments based on the data.

1. **Diploma**

Your son or daughter has options of either receiving a diploma from high school by

completing the requirements or receiving a certificate. Many individuals with a disability

will complete the requirements before turning 22. However, before a student accepts

the diploma in the State of Massachusetts as a parent you should inquire if the schools

district is still obligated to continue services under IDEA. If the student requires services

accepting the diploma would not be appropriate for the student if the school district is

not obligated to continue in providing services. If the student needs the services the

certificate is the alternative to the diploma. The student can still participate in all high

school ceremonies if she/he chooses. Prior to graduating or receiving a certificate,

students have made the decision to apply to a college or university. If you are going to

apply to a college or university you must understand that going to college is not an

entitlement. It is about being accepted into college just like any other individual

applying. You will need to apply to the colleges you are interested in. You will need to

inquire and visit them. If applying to a college you do not need to inform them of your

disability. However, if you do colleges do make consideration during the application

process and more and more colleges are accepting individuals with disabilities. Many

colleges are providing accommodation as long as they are informed of the required

needs and capabilities.

**Section 3:**

1. **What are the adult services and how are they funded**

Once an individual had been deemed eligible to receive services a state agent is

assigned to assist in the transition process and identify what services the individual is

eligible for. In Massachusetts, DDS will assign a turning 22 coordinator, who attends

the Individual Transition Plan meeting and meets the student and the student’s family.

The turning 22 coordinator will develop a transition plan with the family, student and

other professionals that form the IEP/Transition team. This transition plan identifies the

types of services the individual will need when he/she transition to adult life.

DDS provides services for residential/community living (independently with

supports, shared living, residential group homes), family supports, and day programs

(community based day supports, employment, center-base work, individual supports)

Community living supports allows a person to live independently or with their family. If

living independently the individual will receive over 15 hours of supports per week. If

the individual lives with his/her family he/she will receive intensive supports if they have

significant medical, behavioral and skill needs. DDS also funds services for

residential/group homes. The supports are 24 hours that have at least 3 separate

shifts. Individuals will share the home with other individuals who may have the same

needs as your son/daughter. Typically an individual can have at least three to four

“house mates” and staff ratio varies based on the individual needs and capabilities.

DDS also funds homes that specialize in medical and behavioral needs. If this is the

option that best fits your son or daughter you will need to furnish the room. Shared

Living is another option available to individuals with disabilities. A person (s) or

family is identified that will share a home/apartment with the individual. The shared

living provider provides the necessary supports to develop skills, supports the

individuals daily needs and provide supervision.

Day programs are another service that is funded by DDS. There are various

options available; employment supports provides services in obtaining competitive

employment with job coaching supports. Center-based work provides supports services

in a facility and sometimes includes group enclave employment in the community.

Community based day supports is a service that provides vocational training, skill

development, employment supports, and community integration and volunteer

opportunities.

DDS also provides funding for family. The services include respite care,

modifying the environment to fit the individual needs and supporting the individual in

community and other social activities. Individuals who live independently may also

require supports less than 15 hours a week and the supports are in budgeting, medical,

developing skills that one needs to live alone (laundry, cleaning, cooking) and

assistance in learning how to integrate in the community using the community

resources.

An Individual can also receive self directed services. This permits an individual

And/or parents the ability to develop a support plan that grants them the ability to

manage their own services. The individual and family determines how the funds are

spent and can hire their own staff.

DDS arranges and funds person transportation to and from where the individuals

resides. The transportation can be separate and direct or with multiple individuals.

There are programs that DDS does not fund but does provide assistance in

providing information about these services and how to obtain eligibility. These services

are state plan services and are funded by Medicaid. Day HabilitationServices is a

medical model that requires a nurse and consultation in allied health (speech, physical

therapy occupational therapy and behavior). In this program the service is to increase

skill development in self-help, communication, independent living**,** etc. To be able to

receive services one must have a diagnosis, require assistance in skill needs and have

MassHealth. Adult Foster Care is also skill development building and services are

provided in the home. The skills that are to be developed are activities of daily living

grooming, cooking, laundry, money management, integration in the community).

Another option that families can look for in assistance that is funded by Mass Health is a personal care attendant (PCA). This service is 1:1 in home and the PCA is to assist in person care needs.

If a person is not eligible for DDS services there is an appeal process that is filed with the Bureau of Transition Planning (BTP). If not appealing, there are other human services agencies (Massachusetts Rehabilitation Commission (MRC), Massachusetts Commission for the Blind (MCB), Massachusetts Commission for the Deaf and Hard of hearing (MCDHH), Department of Mental Health (DMH) and Massachusetts Office on Disability (MOD).

**Section 4:**

**When should the individual and parents begin the process of looking for adult services?**

Adult services begins at the age of 22 and you and your parents have been

advocating a certain direction for you to take when you enter adult life. You may have

decided that post secondary education is the direction to take once you have graduated

or employment, day-habilitation, residential group home or independent living.

At the age of 14 one can obtained a work permit and here you and your parents

might want to look at adult programs or school systems that can support you in

experience work opportunities. As oppose to going to camps during the summer when

school is not in session or extending the school year, a referral to adult programs can

help in providing the supports and will give you an introduction to what adult programs

do what. This opportunity could continue until turning 22. These programs also allow

for an ease in transitioning to adult services. Parents learn what programs provide

what, what they are successful at and begin to build relationships with DDS and adults

agencies.

At the age of 18 through the age of 20 the transition plan for the future is refined

and you and your parents are introduced to DDS by being referred as a 688 referral. A

turning twenty-two coordinator is assigned. Here is another opportunity to inquire about

adult services and as a parent you need to inquire about those services. The agent

should provide you with a packet that informs you about the services and a list of

venders/agencies that provide services for adults and what each one specializes in.

Some parents during this time have asked the schools district to fund their child

in adult agencies who are authorized to perform educational services. The decision is

based on their son or daughter not being accepted by schools and/or have maxed out of

being able to benefit from the academics. In my experience this has been one of the

most graceful transitions to adult services. The several students that enter the agency

that I work at transition into adult services successfully in that the individual knew what

to expect and what direction they wanted to take. Parents learned how to navigate the

adult services and developed relationships with the agency.

When the student turns 21-22 and is eligible for DDS the turning twenty-two

coordinator develops an Individual Transition Plan. This plan highlights the services that

the individual requires; residential, day habilitation, employment, transportation and

what is required behaviorally and medically. Starting this process early is more likely to

aid the transition into adult life gracefully. Many adult agencies have a process when a

referral is made to their program. Typically the DDS coordinator will inform the agency

of a referral and will invite the agency to the ITP meeting or will set up a tour of the day

program/residential program.

During the tour, parents and the individual provide verbal information about the

individual, what the current supports are and what they are looking for; employment,

medical, day-habilitation, residential, and transportation. The agency then informs

about the services they provide and what the individual could expect. Parents should

compose questions they have prior to the tour.

As this is the first step you should begin this prior to your son or daughter turning

21. You should tour several programs and look at several group homes. If you wait

this long it could jeopardize a flow in services. Typically once the student turns 22

educational services start and the individual starts his adult services. Sometimes when

parents wait the transition could be rushed along and decisions are made out of haste

and anxiety increases. Typically, the best age to begin looking is at the age of 18 or 20.

However, during the tour both parties are evaluating if this is the appropriate selection

for the individual.

After the tour and the individual and parents are interested, the next step is to

have the written referral documents sent to the agency for *their* review. The referral

information is what you have in your portfolio when you applied for eligibility. There

should be the most current IEP plan, progress summaries and any other documentation

that will aid in the decision of acceptance by the agency.

The third step is for the agency to go to the school system and speak with the

students teachers, clinicians and therapist. During this visit the agency is observing the

student and interacting with him/her. Some agencies will visit several times prior to

making the decision.

The fourth step is acceptance. The agency notifies the turning 22 coordinator.

The coordinator will inform the parents and individual about being accepted. If

accepted, most agencies will write a letter of acceptance informing them when they will

start and what they will require. If employment (state ID, birth certificate, passport and

social security are required) If Day Habilitation (medical cards, authorization from

doctor, immunization, annual physical) If residential you will need all forms of ID and

health records. The agency will then schedule times for the student to visit the program.

During the visits the individual will meet who they will be working with or living with, who

the staff familiarize themselves of the routine and etc.

Lastly DDS will secure transportation and authorize the vender to provide

services. Once there is a contract the school system and the adult agency develop

plans for the transition. Some individuals do well having a familiar staff with them for a

short period of time and others just start as letting go is difficult. This process is

individualized and based on my experience having the individual just start has been a

smoother transition.

**Section 5:**

**Conclusion**

To transition gracefully into adult services is about careful planning, starting

early, learning to navigate the system and developing the skills that allow a person to

function as an adult. It is about having a support system and developing ongoing

supports so that there is the continued opportunity to develop ones potential. Transition

provides a wide range of welcoming opportunities and will allow the individual to feel

self worth as all the planning is focused on enhancing the person’s life.

In my 25 years in working with adults and transitioning adults with autism or other

developmental disabilities, transition needs to be individualized, the process in

transitioning in adult services should start early and decisions made by age 21as to

what programs the student is going to attend. Knowing what is going to happen

reduces the anxiety and helps the student to adjust in leaving the school system

(teachers and peers).

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