



After the School Bus Stops Coming... It's Not As Scary As You Fear!

Entitlements to Eligibilities
—for Young Adults with Disabilities—
Elucidated and Explained

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Overview

The article provides an overview of the processes, and agencies and funding mechanisms involved in the transition to adult services for students with disabilities in Maryland. The existing literature pertaining to transition questions is disparate, complex, confusing and off-putting for families trying to imagine and plan for the future of their transitioning youth with disabilities. The information in this article:

- disentangles the rules and regulations that apply to individuals;
- clarifies the roles of various governmental entities and shows how they intersect to support the efforts of individuals and families who are evaluating work and living options; and
- explains how their missions have evolved and changed over the years.

It is crucial for families to understand how the disability rights movement has evolved over these past 10–20 years if they are fully to appreciate the programs and opportunities that exist for people with disabilities and that are evolving by the day in the State of Maryland.

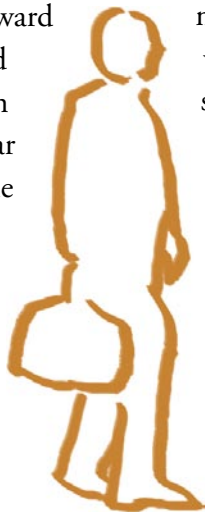
Readers who will benefit from this article include:

- Youth with disabilities, families, advocates, caregivers;
- Vocational Rehabilitation personnel including administrators, rehabilitation counselors, vocational evaluators, rehabilitation teachers; assistive technology and medical rehabilitation professionals;
- Secondary educators including directors of special education, transition coordinators, special education teachers, career and technology prep teachers, guidance counselors and pupil services workers; psychologists, school health professionals; and juvenile justice professionals;
- Developmental disabilities and mental health professionals (counselors, community rehabilitation and psychiatric rehabilitation program staff serving transition age youth, service coordination, administrators); and
- Development professionals/One-Stop Centers disability navigators, benefits specialists, policy makers, employers, and other advocates interested in the successful transition of youth with disabilities to productive lives.

Introduction

This past May, my son Alex turned 19. In two years' time, he will exit the school system. For the past 14 years, his life—and mine—have followed the rhythms of the school year: from Monday to Friday, he's been up by 8am, hopped on the school bus, and returned home around 3:45pm daily, apart from Wednesdays, early dismissal day, when he has turned up around 1:45pm. His team of teachers and therapists have devoted those two hours, every week, to reviewing the difficulties their students face, and assessing how well, or poorly, they are progressing toward the enumerated goals of their Individualized Education Plans (IEPs). Summers have been a mixture of camps and extended school year (ESY) programs, combined to ensure that he retain the skills that he has worked so hard to master in the course of the school year.

When Alex exits the school system, all this will change and he will leave the vibrant community that has sustained in him so many ways, formal and informal. In fact, the stories that I've gathered from parents whose children have left school have been disheartening. In one case, a young 21-year-old woman has a job for 4 hours a day, 5 days a week, in supported employment. Her mother ferried her to and from work until, eventually, *Metro Access* stepped in to take on that role. The rest of the day has to be structured by



mom. In the case of another family, their 30 year old daughter works only 16 hours a week in a supported employment situation. In yet another family, their 59-year-old son no longer works—having lost his job as a volunteer—and sits at home idly watching television and becoming more unfit and unfocused by the day. His mother has neither the energy nor the resources to create a different scenario for him. In all these cases, the moms have taken up the roles they played when their children were pre-school toddlers—managing and maintaining their children's work and leisure activities, with very modest supports.

Despite our efforts to raise our children to become as independent as possible, to infuse them with love and support and to bolster their self-esteem and self-confidence, they may be unable to go off to college, explore the wider world, and live independently. Many of us—especially mothers—also face the prospect of having to resume these earlier parenting roles at the same time that we must care for elderly parents and in-laws. Indeed, many of us are already, or will become, dramatic examples of the *sandwich generation*.

While these dual responsibilities are certainly daunting, in some respects they are mirror images of each other. Raising children requires

that parents step back, little by little, allowing a wholly dependent newborn gradually to discover her abilities and talents and become fully independent. With parents, it is the reverse. People to whom we looked for guidance and support yield their independence, little by little, and often with resistance and resentment. The trick in successful parenting, as well as the successful shepherding of our elders, is to know what balance to strike between dependence and independence at various stages in their lives. Moreover, as anyone who has these responsibilities can tell you, there are no prescribed steps that must be taken at particular points. The process, like so much else in life, is a dance of accommodation and restraint, with everyone making up the steps as they go along. In contemplating the future for my son it has helped me greatly to keep these twin processes in mind: my wish for him—as for my aging parents—is the greatest independence he can achieve, with whatever supports he might require for a successful and rewarding life.

So, what kinds of work opportunities and activities exist for a young adult who cannot expect to hold a competitive job in the community? What kinds of housing options are available for a young adult who cannot live on his own without supports and services? This article addresses these questions. Agencies—governmental and nonprofit alike—have produced a vast amount of literature on these topics, but I have found them to be complex and confusing. Writing this article has clarified many of the issues for me and I hope it will serve as a helpful blueprint for other families in a similar situation. This discussion focuses on Maryland, but there are comparable programs in other states.

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Also, bear in mind that the information presented here is current today but might change tomorrow: systems change, laws change and funding streams change.

Is it really true that after years of schooling—with structured activities, well defined goals and high expectations—the future is so bleak? Almost every parent I have spoken to has affirmed that their adult children have regressed, become less able and more dependent in the years following their exit from the school system. This issue is certainly on the national radar. A *Wall Street Journal*¹ story entitled “Aging Out”: *When Disabled Children Get Too Old for Public Education*, described the dilemmas that parents face, when at age 21 (22 in DC, 26 in Michigan), their children are no longer entitled to a free and appropriate public education. The era of Individualized Education Plans (IEPs) and dedicated teams of teachers devoting their energies to helping children achieve annual goals comes to an end, and there is no comparable group to pick up the baton and move these now adult children along. Now, it is primarily up to parents to put in place the necessary supports for their future.

That’s not to say that parents are entirely on their own. The [Division of Rehabilitation Services \(DORS\)](#), a division of the State Department of Education, picks up where the school transitioning team left off, and assists individuals with disabilities in a variety of ways: with further training, guidance and short-term supported employment. So, young adults who were once accustomed to having IEPs, might develop—under the auspices of DORS—an Individualized Plan for Employment (IPE). The IPE, like the

¹ D1, 30 June 2005.

IEP, sets goals, suggests ways in which they might be achieved, and identifies the services needed and who can provide and pay for them. Also, the [Developmental Disabilities Administration \(DDA\)](#), under the umbrella of the [Maryland Department of Health and Mental Hygiene \(DHMH\)](#), will have been informed the year prior to a child's leaving school, that she may, for instance, require residential services because it's thought she'll be unable to live independently; or that she may require daytime services, if it's thought that she'll be unable to work and support herself. In that case, the DDA assists in developing an Individual Plan (IP) for its clients. Finally, a young adult who is unable to support herself may also

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qualify for Medical Assistance (MA) or Medicaid, a form of health insurance. (www.dors.state.md.us; www.ddamaryland.org)

Regrettably, establishing the likelihood of these future needs—for shelter, employment and medical services—does not automatically translate into the provision of those services. From this point forward, these young adults are no longer *entitled* to services—as they were once entitled to a free and appropriate education—but are *eligible* for them, if openings and funding exist. The distinction is crucial. A further point: although the DDA will have been informed that a young adult may require services, families themselves must apply directly to the DDA and to DORS for services.



The First Step: Division of Rehabilitation Services

So, how do we maximize the chances that our young adult children will be able to hold meaningful jobs in the community? The answer is complicated. For a start, it begins by discovering the kinds of jobs that our children would want to do, a process that really begins in earnest in their high school vocational programs. By the time our children have exited the school system, they'll have been exposed to a range of jobs and given the opportunity to identify those that best reflect their preferences: for instance, working individually in a quiet and secluded job or perhaps working in a lively setting with other people, where noise and activity pose no impediments to doing their jobs well.

Some of these young adults will be able to do these jobs without supports; many will require some coaching—perhaps intensively to begin with, but tapering off over time. In other words, what your young adult child wants to do might not correspond to what she is actually capable of doing, but it might be within reach with training and other supports. In that situation, the first agency to which a family can turn is [DORS](#), a division of Maryland's Department of Education that subdivides into three units: the [Office of Field Services](#), the [Office for Blindness](#)

and [Vision Services \(OBVS\)](#) and the [Workforce and Technology Center \(WTC\)](#). Families should notify DORS that their child has a disability at age 14. In their junior year of high school, at age 16, those children are eligible for DORS services, although accessing them usually occurs somewhat later, when the child is in the last year of high school and on the threshold of graduating, or is looking towards continued education, up until age 21, to earn a certificate or diploma.

Keep in mind that DORS does not provide direct services, but purchases services like job development and job coaching from vendors that provide [Community Rehabilitation Programs \(CRP\)](#). The CRP vendor provides the direct job placement and job coaching to the client.

As noted earlier, counselors from DORS work with a school's transition team to draft an Individualized Plan for Employment, an IPE, which builds upon components of the student's IEP. DORS' primary objective is to help eligible individuals become competitively employed. Among other things, DORS might provide career counseling, support a student in a job, acquire assistive technology, and advise or coordinate services after the student exits the school system.



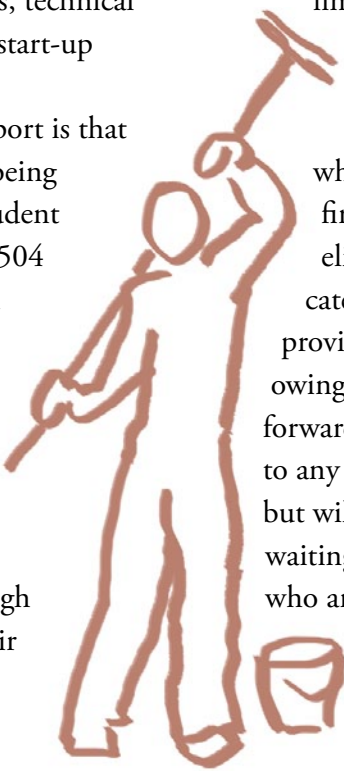
So, for example, a young adult could receive support in preparation for entering college (the [MAST](#) program) or get up to 135 hours job coaching support for a particular job. If she is able to retain that job for 90 days of consecutive employment, the DORS case is closed. If the client's situation changes and she requires support in a new job, she can reapply to DORS and the process begins anew. There is no age limit to apply for DORS support.

Also, young adults who are interested in owning their own business may be eligible to enroll in DORS' *Reach Independence Through Self-Employment* ([RISE](#)) program, which offers individuals with developmental disabilities and mental illness the opportunity to become business owners by providing unique supports, technical assistance and even limited business start-up funds as needed.

The key to accessing DORS support is that its services may not duplicate those being provided by other agencies. If the student is still in school and has an IEP or a 504 plan (a plan that specifies any special accommodations a student might require, enabling her to tackle the regular curriculum), then DORS support must complement what is already being provided. For example, if a young adult is already receiving job coaching services through the local school system as part of their IEP, she can still apply to DORS for

particular help that is not addressed by that program. Similarly, if a young adult receives DDA support (more on that later), she can apply to DORS for particular help that is not addressed by the DDA's program. Families that can identify targeted or discrete needs best are likelier to get support. (For personal help with any problems, you can contact Beth Lash, Director, DORS Client Assistance Program, blash@dors.state.md.us, or call: 800-638-6243.)

Keep in mind that to be eligible for DORS support, a person must have a disability, but having one does not guarantee that support will be given. DORS is subject to the 1973 Rehabilitation Act that requires it to develop a means to prioritize services in the event—given limited budgets—it is unable to serve all those in need. The DORS *Order of Selection* policy stipulates that those with the most significant disabilities which affect their employment be served first and so the agency places those eligible for services in one of three priority categories. DORS has usually been able to provide services in the top two categories, but owing to reduced funding, from July 1, 2007 forward, DORS will no longer provide services to any new individuals in any of its categories, but will place those eligible for services on a waiting list. Individuals on the waiting list who are identified as having most significant disabilities (Category 1) will eventually receive access to services.

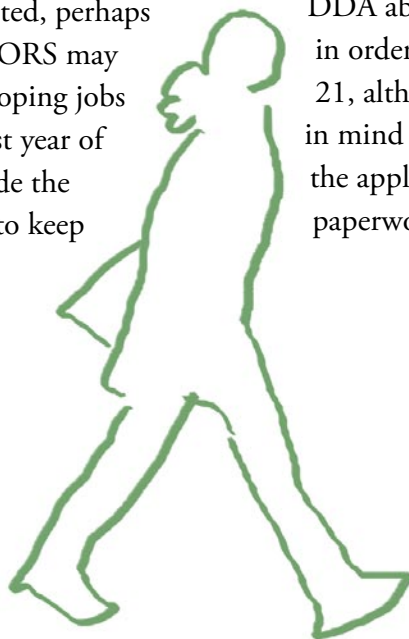


Exiting School: The Governor's Transitioning Youth Initiative

For families of students with a developmental disability who are just preparing to exit the school system, there is a reprieve from joining long waiting lists. The [Governor's Transitioning Youth Initiative \(GTI\)](#), launched by Governor Schaefer in 1989, targets DDA-eligible students after they turn 21, or as they exit the school system after their 21st birthday—for one year. GTI funds may be accessed in that year only, but once they are awarded, individuals can expect to receive long term supported employment or day services. The motivation for this initiative was to provide continuing services for these young adults so that they would not lose the skills they had developed in school while they waited, perhaps for years, on DDA waiting lists. DORS may have assisted young adults in developing jobs and coaching them during their last year of school, and may continue to provide the *short term* support to enable them to keep

a job. DDA funded adult service agencies provide the *long term* skill development and job coaching for eligible students exiting school.

Although both DORS and DDA have Transitioning Youth funding in their budgets, GTI funds constitute a discrete infusion of funds to the DDA for DDA day or supported employment services. GTI funds are not available for students under 21, so exiting 18 year old students who need help should apply both to DORS and to the DDA and, if funding is tight, they will be added to their waiting lists. DDA eligible students who have exited the school system before their 21st birthday should contact DDA about GTI funds when they turn 20 in order to be considered for funding at age 21, although support is not guaranteed. Keep in mind that in order to access GTI funding, the applicant and the school should complete paperwork within specific timelines.



Jobs, Jobs, Jobs

To recap then, as students graduate from school at age 21, [GTU](#) monies are earmarked for them for one year as they transition to the world of work and [DORS](#) is committed to helping them become competitively employed. But not all young adults with disabilities will be able work a competitive job. Currently the [DDA](#) has four different employment or training opportunity models for families to consider:

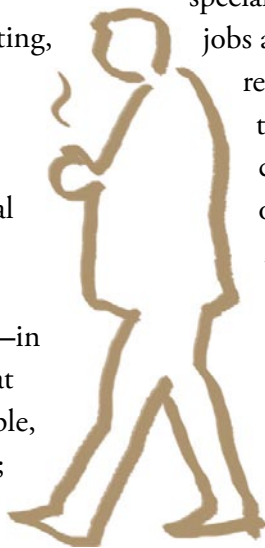
1. Vocational Training (sometimes also known as secured, segregated or sheltered employment) includes vocational assessment, job training or work skill training, and placement programs; it might also involve training in social skills, acceptable work behaviors and money management. These programs usually occur in a segregated setting, where individuals receive a lot of support and supervision, often work together in groups alongside others with disabilities, and work at basic tasks. They earn minimal or no compensation for their work.

Two other forms of segregated employment exist as well: **Enclave Work**—in which a group of 8 or fewer people work at one site together—might entail, for example, being part of a cleaning crew at an airport; and **Mobile Work Crews**—in which 8 or fewer workers move together from job to job—might entail, for example, being part of a landscape crew that moves from one site to another. In these cases, individuals might be paid below the minimum wage, or well above it.

2. Supported employment involves people working in jobs in the community in integrated settings—that is, working alongside people without disabilities—where they receive job supports that vary in intensity, depending on their particular needs. Supports can be ongoing, or fade over time, but these workers are hired by and paid by the employer directly, and receive wages and benefits comparable to those of their co-workers.

3. Competitive employment entails employment where few or no supports are required to acquire and hold a job successfully and the individual is fully integrated in the community. These jobs usually require specialized skills, and people who find these jobs are full participants in the work force, receiving wages and benefits comparable to those of their colleagues. Supports can be provided for these individuals over and above what they might receive from their colleagues at work.

4. Self Employment or Supported Business Enterprise entails employment in a business established or owned by the individual, including a micro-enterprise (fewer than five employees). The individual may require supports, including staff supervision, to successfully maintain the business. DORS' *Reach Independence Through Self-Employment* ([RISE](#)) program was designed to support individuals with these aspirations.



The Movement Toward Integrated Employment vs. Sheltered Workshops

The nationwide movement to discourage sheltered employment—and indeed to dissolve sheltered workshops altogether—is animated by the belief that for all individuals work is a civil right and that separating workers into discrete workshops is no different in essence than segregating women from men, or races from each other. The solution to the inequities that gender and racial divisions wrought was to eliminate the barriers. The same solution applies to those with disabilities. These arguments mirror in spirit those made by parents who demand that their children with disabilities be educated alongside their peers in public schools. To be clear, proponents of integration in the workplace are not arguing that unqualified people be given jobs in the community any more than they are arguing that a student with a learning disability be placed in a classroom of high functioning students without a suitable aide to assist. Rather, they argue that each individual, regardless of ability, ought to be able to find a useful job, and that if supports are required for her to succeed at that job, then they must be provided so that every person can be a productive member of the community.

The tide of opinion has moved strongly against sheltered workshops, reinforced by the

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1999 Supreme Court decision, *L.C. & E.W. vs. Olmstead*, which ruled that “it is a violation of the Americans with Disabilities Act for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community based setting.”² Maryland’s regulations now discourage adding people to institutions and the state is actively trying to move people into community settings through its *Money Follows the Person* grant, recently received from the [Centers for Medicare and Medicaid Services \(CMS\)](#).

Vermont has closed every one of its sheltered workshops. In fact, the movement toward integrated employment—inspired by principles of equity—is not always reinforced by basic economics. In some cases, putting people to work in sheltered workshops is less expensive than finding them jobs in the community and supporting them there. Intensive job coaching and the 1:1 staff to support someone off-site—along with transportation—is an expensive undertaking. Nevertheless, the momentum toward integrated employment continues apace.

Some resist this momentum. Just as many

² National Conference of State Legislators, *NCSL News*, March 29, 2001

parents and educators favor a range of schools offering a continuum of services that allows some children to be educated in classrooms and schools set apart from their typically developing peers, the same is true in the realm of employment: many young adults thrive when they work together in sheltered workshops and their families fully support their existence. Still, sheltered workshops may not be around much longer. Under these circumstances, it is worth considering the benefits that sheltered workshops provide people with disabilities, so that perhaps those benefits can be recreated in other venues.

To illustrate, young adults employed in sheltered workshops often include those who dislike change and require consistency, enjoy jobs that are repetitive, and find comfort in being with the same group of people on a regular basis. This might describe equally how many typical workers feel about their jobs. Indeed, one of the things I've learned in exploring this subject is that many clients who have been moved from sheltered workshops to supported placements can handle their new work assignments, but many are deeply depressed by the isolation they experience at their new, community based jobs.

The simple reason is that they

The crucial point to remember is that supporting them in community workplaces could contribute to their further isolation in the absence of thoughtful efforts to create new webs of social connections and supports.

do not have friends at work as they did in their sheltered workshops. What does that mean? For many of our young adults who are on the autism spectrum, friendship connotes something quite distinct. These young people do not interact with one another very much; they hardly ever pick up the phone simply

to make contact, and schmooze; they remain on their own quite contentedly, without seeking the company of others. For these people, who tend to isolate themselves from others, the mere existence of a sheltered workshop provides a community

of like-minded, sympathetic peers, to whom they appear neither strange nor off-putting, and by whom they are fully accepted, just as they were when they were in school. Opponents of segregated employment argue that grouping together individuals with social, behavioral and communication challenges offers them fewer opportunities to develop those capacities than if they were in integrated employment. The

crucial point to remember is that supporting them in community workplaces could contribute to their further isolation in the absence of thoughtful efforts to create new webs of social connections and supports.



Finding the Right Job

For families trying to imagine the future for their children with disabilities, the challenge is to try to identify four things in particular.

- First, what really interests your child?
- Second, what does it take for her to be comfortable and focused? Put another way, what physical and emotional circumstances are likeliest to enable her to succeed at a task, and then, at a job?
- Third, is there a job in the community that can marry the first two criteria successfully?
- Finally, can she find through her job the fellowship of friends and if not, how can that be supplemented?

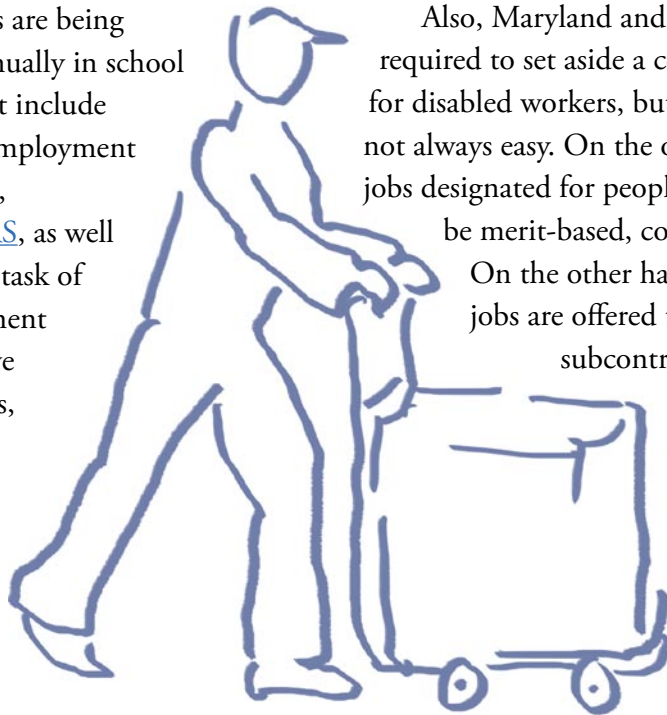
The first two questions are being asked and answered continually in school by transitioning teams that include teachers and counselors, employment specialists and job coaches, representatives from [DORS](#), as well as family and friends. The task of finding jobs falls to placement specialists, with the creative input of family and friends, and eventually, agencies. Developing a fellowship among colleagues and a network of friends are probably the most difficult issues for

families trying to launch their young adults on the path to independence.

It is worth keeping in mind that if there are jobs that would particularly interest your young adult, you may be able to appeal to more than the generous spirit of the employer you approach. The [Maryland Disability Employment Tax Credit \(MDETC\)](#) was developed as an incentive to businesses to employ people with disabilities: it allows employers to claim credit for employees with disabilities hired on or after October 1, 1997 but before June 30, 2008. Often employers don't know about this and other incentive programs and DORS can advise them on the state's rules.

Also, Maryland and federal agencies are required to set aside a certain number of jobs for disabled workers, but finding these jobs is not always easy. On the one hand, government jobs designated for people with disabilities may be merit-based, competitive positions.

On the other hand, many government jobs are offered through government subcontracts, and DDA-licensed agencies bid to fulfill the obligations of the contract. In those cases, individuals are not hired on the basis of merit directly by the state or federal agencies;



instead, they are subcontracted by the agency bidding to the state for a group rate on behalf of its disabled workers. For example, the [NISH](http://www.nish.org) federal set-aside program has subcontracted the work for the *Mobile Work Crew* at BWI Airport that is very well paid for its cleaning services. (For more information on federal programs, go to www.nish.org; for the State of Maryland set-aside programs, go to www.mdworks.com.)

For families in Montgomery County who would like to learn more about the kinds of jobs available in the community, *Montgomery Works* has a twofold mission: to help Montgomery County workers who are entering and re-entering the workforce; and to meet the current and future needs of local employers. Fulfilling those dual goals might entail job carving—developing a job based on a person’s abilities in combination

with systematic workplace analysis—as well as coaching, workshops and training. *Montgomery Works* is Montgomery County’s *One Stop Workforce Center*, one of over 3,000 across the country. *Montgomery Works* currently has three different initiatives which provide assistance for jobseekers with disabilities: the *Disability Program Navigator Initiative* (www.mdworkforcepromise.org/dpn.html), the *Montgomery County Government Public Intern Program* (www.montgomeryworks.com/jobseeker_services.asp), and the *WIA (Workforce Investment Act) Youth With Disabilities Project* that offers customized employment services to a limited number of transitioning youth during the year they exit from high school. (Go to www.montgomeryworks.com for more information.)

The Developmental Disabilities Administration and Maryland's Medicaid Waivers

DDA and HCBS Waivers

Where does the [DDA](#) fit in to the picture? The DDA administers funds for community services for people with developmental disabilities, and as we've seen in the context of jobs, the DDA may provide them with long term skill development and job coaching support. The DDA may also provide housing support services. I address housing issues in a separate section.

Remember, a young adult unable to support herself may qualify for Medicaid. In the past, Medicaid recipients had to be housed in institutions, nursing facilities or hospitals, but beginning in 1981, Title 19 of the Social Security Act gave states the option to disregard—or *wave*—those requirements so that states could offer alternative living arrangements in support of their disabled citizens and still receive Medicaid support. Maryland's [Medicaid Home and Community-Based Service \(HCBS\) waiver](#) for individuals with developmental disabilities, operating continuously since 1984, has made it possible for people who would otherwise be institutionalized to live in the community with needed supports.

The federal government matches state waiver funds for those individuals who are in an HCBS

waiver, as well as matching state funds for the health care provided under the Medicaid State Plan. States get different matching rates based on their populations of people living in poverty. Maryland has a 50% match rate because it is a relatively wealthy state—in other words, for every dollar that Maryland spends on state Medicaid services, the federal government provides a dollar as well. Mississippi and West Virginia, for example, get a higher match rate, because they are not as wealthy. In fact, Maryland is the wealthiest state in the nation, but ranks 44th among states in its aggregate spending for people with disabilities.

In order to access waiver services, an individual must receive Medical Assistance (Medicaid). A young adult who receives Supplemental Security Income (SSI) automatically qualifies to receive Medicaid. An individual qualifies for one of the Home and Community Based Medicaid waivers, if she earns no more than \$1,869 per month under the waiver (3 times the maximum amount of money she receives per month from SSI). The Social Security Administration adjusts these amounts annually. Also, the Medicaid applicant may not have assets

above \$2,000 under the waiver. Families often use a certain kind of discretionary trust fund on behalf of their disabled children to shelter assets above that level.

What are the advantages to a family in applying for the HCBS waiver? Once on the waiver, it guarantees the family and individual a *resource coordinator*, access to additional Medicaid services (that include prescription medications and some therapies), needed home and community based services, and the right to request a hearing within 90 days of being notified of any change in services. These benefits target some of the perceived trade-offs in giving up an institutional arrangement—the security that comes with centralized care and medical services, and a ready-made community of people with whom to live.

However, the HCBS waiver has another virtue that has led it to be embraced by state legislatures all over the country. It provides people with disabilities with greater opportunities to live more independently, to live in neighborhoods, and to participate in the civic life of their communities. Like the civil rights and equal rights movements before it, the disability rights movement upholds the view that our communities are enriched by diversity, and that individuals—disabled or not—are entitled to equal rights and opportunities, precisely the same arguments that are made by proponents of integrated employment.

In Maryland, there are two waiver programs for individuals with developmental disabilities under the Home and Community-Based Services (HCBS) waivers. Once a transitioning youth applies to the DDA, the DDA assigns a *resource coordinator* to work with the individual and his family. Typically, that coordinator has a caseload of about 50 individuals, and is assigned to serve

as a resource to help the family navigate services and choose those that best suit their young adult's needs. At the same time, the DDA refers the individual to an independent agency that determines a "level of need" score by assessing the complexity of her needs. That score is one of the elements used by the DDA to develop a budget for the individual. One component of the budget in the Community Pathways waiver is a flat provider rate.

The waiver program is the means to create a package of services tailored to the needs of the individual, but that individual may be on only

one waiver program at any time. For states, a new waiver application is approved by the Centers for Medicare and Medicaid Services (CMS) for 3 years, and can be renewed thereafter for 5 years. An approved waiver application is a contract and the state

must do what it said it would in the application, although the terms of that contract can be amended during the life of the waiver. Although individuals must choose one waiver program, they can change from one to the other if they so choose as long as they meet all of the eligibility criteria for the waiver and there are available waiver slots.

By law, each state must assure the health and welfare of those on its Medicaid rolls by means of a quality assurance system and families do have appeal rights if the plan, budget or needed services are denied by the state. Keep in mind that one person's standards for assuring quality may not correspond to your own; furthermore, when evaluating the health and welfare of a beneficiary, a client's needs may not correspond to what she wants, nor might her decisions about services be the same choices her family would make on her behalf.

The HCBS waiver provides greater opportunities to live more independently, to live in neighborhoods, and to participate in the civic life of communities.

Maryland's HCBS Waiver Programs

What are Maryland's **HCBS** waiver programs for adults who are developmentally disabled? The **Community Pathways waiver (CP)** program provides a range of services—residential, day, employment, transportation among others—that are implemented by agencies that have been licensed by the DDA. The **New Directions waiver (ND)** program allows individuals and their families to design and manage their own program. These two waiver programs are very different, but certain rules pertain to both. No HCBS waivers—neither Community Pathways nor New Directions—give cash payments to the person receiving services, pay for room and board, pay for what the individual's school or **DORS** pays for, or pay for the things that are covered by the Medicaid State Plan. HCBS waivers can pay for additional Medicaid services, but only when standard benefits are used up.

Community Pathways Waiver

How does **Community Pathways** work? The family that chooses the Community Pathways waiver must select an agency from the list of **DDA** licensed agencies that provide community based support services in their region. For

Families must choose among more than 26 agencies that are licensed to fulfill these waiver obligations.



example, Montgomery County currently has a list of more than 26 agencies that are licensed to fulfill these waiver obligations, but families can choose any agency in the state of Maryland.

These service providers offer some combination of residential, day and support services, and families must choose among the programs that each agency provides. The DDA distributes service dollars for individuals directly to the agency providing these comprehensive waiver services. (For a list of DDA-licensed providers for Maryland, go to www.ddamaryland.org/coordinators.)

Among other things, agencies provide day habilitation and vocational services, job support for those in supported employment, transportation services, recreational activities, social opportunities, assistive technology, and so forth, depending on the needs that have been identified in the client's Individual Plan (IP). (Note that the DDA develops an IP, DORS an IPE, for individual clients.) The agency arranges all the services. Note that not all agencies are alike: some offer more self-directed supports, others fewer. Even so, all agencies are required to tailor their services

to each individual. So, for example, an agency might coordinate supports so that a client who works only part time can combine work with

structured activities at a day center when her job is done.

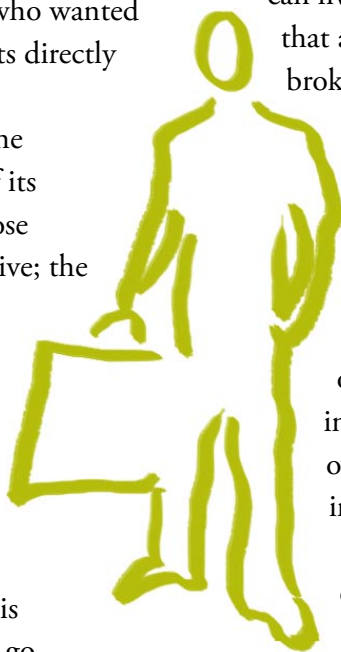
New Directions Waiver

In contrast to the [Community Pathways](#) waiver, the [New Directions](#) waiver provides the individual and her family the opportunity to direct needed services themselves. In 2000, the Robert Wood Johnson Foundation released the results of a self-determination project that spurred the federal Centers for Medicare and Medicaid Services ([CMS](#)) to develop an **Independence Plus Template** and invited states to use it in designing their own waiver programs. The **New Directions** waiver was Maryland's response to individuals and families who wanted to take charge of their service supports directly and eliminate intermediary agencies.

Self determination is the key to the New Directions program, and two of its proponents relish the *freedom* to choose where and with whom they want to live; the *authority* they have over the dollars earmarked on their behalf; the *support* they receive in organizing those resources most effectively; the *responsibility* for spending this public money wisely; and the *confirmation* that people with disabilities are central in designing this new system.³ (For more information, go to www.dhmd.state.md.us/dda/waiver.htm, and www.tash.org/mdnewdirections.)

Here's how it works. Under New Directions, the individual is more involved in directing how,

Under New Directions, the individual is more involved in directing how, when and by whom, services are delivered.



when and by whom, services are delivered. As with Community Pathways, service dollars are awarded on the basis of the individual's needs, but in this case the money does not go to a service provider. It goes to one of two Fiscal Management Services (FMS), whichever one the individual prefers. The FMS then pays for approved services out of the individual's budget, monitors that budget and provides the individual detailed monthly statements.

The individual hires a *support broker*, someone who works for the individual and assists in determining what kinds of services or supports the person needs and wants, helps recruit and hire staff, and ensures that supports are in place so that the individual can live successfully in the community. Note that a family member could be a support broker. Under this waiver, the individual does not have an Individual Plan (IP) that the service provider will implement. Instead, the individual has an Individual Plan and Budget (IP&B): Now, the individual is in charge of her own *person-centered plan*, the architect of the kind of life she would like to lead in her community with people of her own choosing to support it, within her individual budget.

Under this waiver, the individual is the employer, responsible for interviewing, hiring, training, supervising and even firing those engaged on her behalf. As employer, the individual must also pay employees, and with the help of the FMS, withhold federal and state taxes, obtain workers' compensation and other related insurances, and so forth. The FMS and *support broker* both assist in these areas. Even so, the individual's and their *support broker's* responsibilities under the New Directions waiver

³ *My Life Going Far*, by Edward Willard and Jackie Golden, two pioneers of the New Directions waiver in Maryland. Edward Willard, now at the DDA, offers training and assistance for those interested in New Directions.

are much greater than under the traditional provider-directed system.

As a footnote, it is important to learn that each waiver program has restrictions. So, for example, under the New Directions waiver, you may self-direct services for assistive technology, transportation, family and individual support, personal support, respite, and supported employment; but you may not self-direct New Directions waiver funds for behavioral supports, resource coordination, and traditional day or transition services (although you can still access these services). Nor does New Directions provide

The grim reality is that despite the variety of programs to choose from, there may be neither openings nor funding to help transitioning youth with work and daytime activities or to place them in suitable and desirable settings.

residential services, though it will provide the necessary staff to support someone to live in their own or their family's home. The resource

coordinator assigned to you from the DDA can advise you on these matters. (For details go to www.ddamaryland.org/waiver.htm#newdirections.)

The grim reality is that despite the variety of programs to choose from, there may be neither openings nor funding to help transitioning youth with work and daytime activities or to place them in suitable and desirable settings. I address this topic in detail in a separate section entitled **The Eligibility Conundrum** that appears just after the discussion on housing.

Housing

As mentioned above, licensed agencies under the [Community Pathways](#) waiver may also provide residential services for their clients. So what kinds of housing options are available for adults with developmental disabilities who cannot live on their own without supports and services? The good news is that there are many.

In Maryland, the DDA offers three distinctive kinds of services for disabled adults.

- People can be placed in an institutional setting (known as an Intermediate Care Facility for the Mentally Retarded (**ICF/MR**)). Maryland has four such residential centers, although one, *The Rosewood Center*, is slated to be closed in 2008.
- Under the **Community Pathways** waiver, there are several community based living options among which to choose. Keep in mind that the **Community Pathways** waiver is administered by non-profit providers licensed by the state that serve residents without regard to race, religion or national origin.
- Finally, under the [New Directions](#) waiver, individuals and their families can design their own living arrangements. **Community Pathways** options vary among

The good news is that there are many kinds of housing options available for adults with developmental disabilities who cannot live on their own without supports and services.

the non-profit agencies. For instance, the [Jewish Foundation for Group Homes \(JFGH\)](#), a non-profit agency founded in 1982 and operating in Montgomery and Fairfax counties, provides four different kinds of homes for people with disabilities. They include group homes, where 6 people or fewer live together as house-mates; alternative living units (ALU), where 3 or fewer people share a living space; community-supported living arrangements (CSLA), where individuals who live independently in their own dwellings or apartments, or at home with their families, may receive support services; and individual support services (ISS) for those receiving 10 hours of support or less per week. (www.jfgh.org)

[Bello Machre](#), a non-profit agency founded in 1972 and operating primarily in Anne Arundel County, offers a different mix of options. There is campus living—where 5 group homes, housing 5-6 individuals each—open onto a common courtyard; community living—where 3 or fewer individuals share a home; family living—where an individual may have a room with a family, or have an apartment, but live fairly independently; family and individual support services for people

who live at home; *Bello Machre* also provides respite care services, 24 hours a day, 7 days a week, during family hospitalizations, emergencies and vacations (www.bellomachre.org).

For both the *JFGH* and *Bello Machre*, and many other non-profit agencies like them throughout the state, the mission is to place individuals with disabilities in settings that typical adults might choose to live in—in neighborhoods—to enhance the opportunities for inclusion and participation in the community. Moreover the homes they administer are scattered widely in their respective areas (*JFGH* currently serves about 150 people in 20 homes, 2 ALU and 44 apartments in the metro DC area. *Bello Machre* manages 54 homes and serves about 150 people in Anne Arundel County). For both *JFGH* and for *Bello Machre*, residents work during the week—supported or otherwise—or attend day programs, so that they can continue to develop their abilities and talents as individuals and as productive members of society. When they are not working, residents participate in leisure activities—like their typical neighbors—with the assistance of agency-provided vans that take residents on outings, and even on vacations.

Note that neither the **Community Pathways** waiver nor the **New Directions** waiver can pay for

room and board costs, but **Community Pathways** does provide residential services. In this case, room and board costs come from the individual's SSI, but the individual retains a small portion of those SSI funds as an allowance for personal needs. Indeed, under the Community Pathways waiver program, some agencies will work with the individual to select a roommate and location for a home.

The **New Directions** waiver, the self-determination initiative, takes the spirit of the **Community Pathways** model one step further. New Directions does not provide residential services. Instead, it will provide the necessary staff to support the individual so that she can live in her own or her family's home. Here individuals and families have greater control and choice over the community supports they receive and work with service coordinators to create living arrangements tailored to that individual. These include identifying whom the person would like to live with, where, and in what type of home; hiring the most compatible staff; and organizing work and activities. For example, the Jubilee Association of Maryland (www.jubileemd.org) and The Arc of Maryland and its statewide chapters are two organizations that work closely with individuals and families to design these personalized programs. (www.thearcmd.org and www.thearcmd.org/chapters for more information.)



Housing: Costs, Level of Support and Advocacy

The movement away from institutional to home-based housing has evolved over time, in part in response to claims that institutional residents suffer from abuse and neglect and, in part, to claims that institutions that house the disabled are far more costly to run than individual homes in the community, a crucial variable for states grappling with the financial responsibilities of serving their citizens in need. The evidence for the latter claim is disputed.⁴ Even so, let's consider some of the logistical factors that contribute to the costs of providing quality living care in different settings. As to which settings provide a better quality of life, we'll come to that later.

Institutional costs have been high because the populations they serve tend to have greater needs: these are residents with severe and profound disabilities, who require often complicated medical care, and for whom supervision is needed around the clock. As these people age, the costs associated with their care rises too, but medical and habilitative supports are available

on-site. To compare, people placed in homes have tended initially to have fewer needs because their disabilities are less severe. But even in home settings, problems arise as residents age and additional medical care may be required. For example, people with Down's syndrome are prone to obesity and the early onset of aging. Until recently, most didn't live beyond middle age, but among those who do, many develop Alzheimer's. These individuals, once widely mainstreamed in our communities, will require intensive care and supervision as they age, the kind of care that may no longer be feasible, or affordable, or safe in a home-based setting.

For individuals who are placed in homes, the support teams are quite different from those in institutions. Decentralized staffs—scattered through many homes—cannot easily be supervised, nor can medical care be rationalized. For those who choose community based settings for their loved ones, the responsibility for hiring staff to assist residents in the home falls to the particular agency that runs it. A *JFGH* home with 5 residents, for example, will have a full-time residential counselor (one for weekdays, another for weekends), in addition to part-time staffers who come in to assist in the mornings as



⁴ "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research", by Kevin W. Walsh, Theodore A. Kastner, and Regina Gentlesk Green, in *Mental Retardation*, volume 41, number 2: 103-122, April 2003 (www.vor.net).

residents prepare for their workday, or in the evenings as they prepare to wind down for the evening. Meal preparation, job sharing around the house, bedtime routines may all involve the assistance of additional staff, as well.

Because there is no central chain of authority to supervise such a disparate staff spread over so many different sites, Maryland established the [Office of Health Care Quality \(OHCQ, www.dhmh.state.md.us/ohcq\)](#), from which inspectors are dispatched—often unannounced—to inspect homes as well as ICF/MR institutions and confirm that the services promised are in fact being delivered. Indeed, both the [JFGH](#) and [Bello Machre](#) perform their own spot-checks on people they have employed to staff their homes, to assure quality care. Monitoring staff—whatever the setting—must be reinforced by good communication among families, caregivers and service coordinators. Abuse and neglect are just two possible consequences of disengagement, scenarios to be avoided at all costs.

Maryland’s residents with disabilities and their families are particularly well served by the

Inspectors are dispatched—often unannounced—to inspect homes as well as ICF/MR institutions and confirm that the services promised are in fact being delivered.

presence of two advocacy organizations that lobby on their behalf. The [JFGH](#) and [Bello Machre](#) belong to the [Maryland Association of Community Services \(MACS\)](#)—a nonprofit organization of more than 100 service providers—that advocates for program excellence, high standards and accountability in the provision of services for the disabled in their communities, and that has included supporting wage initiatives for those who work with the disabled ([www.macsonline.org](#)). Earning a decent wage is a very important issue given the high turnover rate among people working in these positions.

At the other end of the spectrum, [The Arc of Maryland](#) works directly with families and individuals with disabilities. What began in 1950 as a small group of concerned parents has grown to become the largest statewide advocacy group with a broad mission that includes sustaining “a person-driven service delivery system that incorporates the preferences, addresses the needs and protects the rights of persons with disabilities” ([www.thearcmd.org](#)).

Together, [The Arc of Maryland](#) and [MACS](#) do invaluable and complementary work on behalf of our fellow citizens with disabilities.



Private Housing Alternatives

To sum up then, among the publicly funded living arrangements in Maryland, people with disabilities might live in institutions, or in some kind of group home or in an apartment. But there are also private alternatives, including those where disabled residents might live among typical families in a communal setting. One example is [Camphill](#), an organization “dedicated to social renewal through community building with children, youth, and adults who have developmental disabilities... in which all participants flourish” ([www.camphill.org](#)). Meaningful work is an integral part of communal life, and every individual contributes to the life of the community based on her ability. This is yet another lifestyle option for families to consider, one inspired by Rudolf Steiner and his notion of theosophy. [Innisfree Village](#), in Virginia, is another residential community

There are also private alternatives, including those where disabled residents might live among typical families in a communal setting

that supports adults with mental disabilities ([www.innisfreevillage.org](#)).

Of course, people with disabilities could also live in their own homes—houses or condos, for example. These individuals may own their homes

outright and doing so does not prejudice their SSI and waiver eligibilities. All the same, complications might arise in these cases: for instance, who would pay for the cost of maintaining the home? Could the individual

who owns the home be subject to pressure from others—what lawyers refer to as *undue influence*—and be persuaded to sign a deed of sale? These are among many issues that must be tackled, including the fact that upon the death of the individual, the home would be claimed by the State of Maryland to offset Medicaid payments that were made on her behalf.



Trusts, Assets and Housing Issues

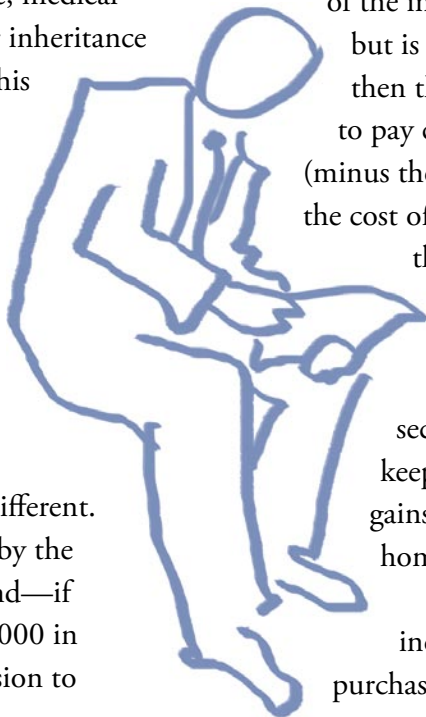
To avoid these kinds of complications, families in Maryland have been able to shelter assets above \$2,000 by creating special **Discretionary** or **Supplemental Needs Trusts (DTs or SNTs)** on behalf of their disabled children. In these cases, an individual does not own the home outright. Instead, the trust created on her behalf would own the property.

For those families able to purchase a home for their children with disabilities, there are a number of things to keep in mind. First of all, there are two kinds of **Discretionary Trusts**: the **First Party Trust** is created with assets of the person with the disability, for instance, medical malpractice monies awarded to her or inheritance funds bequeathed directly to her. In this case, on the death of the individual, there is a payback provision: any monies that have been spent by the state on behalf of the individual must be reimbursed drawing from the assets that remain in the trust upon her death. Whatever remains after that can be distributed to secondary beneficiaries.

The **Third Party Trust** is a little different. In this case, the trust has been set up by the families on behalf of the individual and—if the individual has no assets above \$2,000 in her name—there is no payback provision to

the state. In other words, none of the assets in a third party trust can be garnered by the state to offset Medicaid payments that were made on her behalf. Upon the death of the individual—the primary beneficiary of the trust—any assets that remain in this trust will be passed on to the secondary beneficiary named in the trust. That could be a sibling, an agency, or a charity, to give just a few examples. Whatever is passed on to the secondary beneficiary is evaluated, and if there are capital gains at the time it is sold, then the beneficiary will have to pay tax on those gains. So, for example, if a condo was purchased on behalf of the individual at a cost of \$100,000, but is sold at \$200,000 upon her death, then the secondary beneficiary will have to pay capital gains tax on the difference (minus the *step up in cost basis*—that is, the cost of any improvements made to the property from the time it was bought that added value to its base price). To further complicate the story, if the secondary beneficiary chooses to keep the home, there are no capital gains taxes to be paid, not until the home is finally sold.

First Party Trusts may also include property assets that were purchased before the individual becomes



an adult. From that point forward, the trust can only buy a property for the individual with disabilities to live in. Upon her death, after all funds are paid back to the state for any monies that were disbursed on her behalf, any remaining trust assets are appraised at the beneficiary's death and receive a *step up in cost basis* to minimize capital gains taxes that would be paid by secondary beneficiaries.

There is one final new development to consider: in March of 2007, the Maryland House adopted [HB 717](#), a law that provides a *homestead exemption* for homes in a **First Party Trust**. If that trust has few assets and income—owing to a small initial endowment or to the spending down of the capital over time—the trustee may access programs that benefit

limited income homeowners such as low interest loans or grants to repair or maintain a home. Finally, property in such a trust could qualify for a Homeowners Property Tax Credit as well. **Third Party Trusts** do not qualify for the *homestead exemption*.

The **Discretionary Trust** laws that have been developed on behalf of individuals with disabilities certainly make it possible for more families to purchase a home so that their loved ones can remain in affordable housing, but as the brief discussion above illustrates, there are many financial considerations to keep in mind when purchasing property. Families must consult with appropriate advisers who can help them evaluate their particular circumstances and make the best recommendations on behalf of their loved ones with disabilities.

Weighing Housing Options

While it is clear that there are many different and attractive living options to consider for individuals who cannot live independently, Maryland has for several years favored the model of the community-based program, in the belief that the quality of people's lives is greatly enhanced when they are integrated into their communities and can age in place. The evidence for the success of this approach is clear. For the *JFGH* and for *Bello Machre*, the group homes are not simply living quarters, but the locus of family and friendships. Housemates live together, celebrate together and vacation together just as families do. Moreover, both these agencies have succeeded in attracting volunteers to befriend their residents, and involve them in their communities.

By the same token, there are individuals who thrive in larger, communal settings, where the prospect of meeting more people—whether disabled or not—is an asset, and for whom the safety of secure boundaries is an important factor in their well-being.

The bottom line is that we want our family members to be safe, happy, loved and engaged with other people. It's fitting

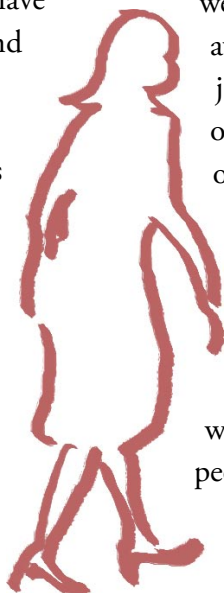
The quality of people's lives is greatly enhanced when they are integrated into their communities and can age in place.

at this point to reflect back on the situation of our parents and in-laws as they age, and whose circumstances mirror—in reverse—those of our growing children. How do we provide our emerging adults the latitude to discover their own independence, while simultaneously erecting the appropriate supports that they still need? On the one hand, the quality of care must be excellent.

On the other hand, so too, must the quality of life. How we combine these elements ultimately depends on the individual who needs to be cared for,

and the outcomes one can reasonably hope for on their behalf. It seems to me that families are well served by the spectrum of living options available to young adults beyond school age, just as they were by the range of educational opportunities in school. Indeed, the spectrum of living options available to the aging provides a handy blueprint for parents who are trying to imagine what the future of their children with disabilities might be.

The importance of maintaining a range of options becomes clearer when you think about the kinds of homes people live in over a lifetime: individuals grow up, leave the family home, live in the communal setting of a college dorm,



graduate from there to a group home with other young people, live alone, find spouses, raise families in a single family home, and then as empty-nesters, often choose to move to a retirement community where the residents are roughly all the same age, and where, when necessary, they can shift to assisted living quarters.

This kind of lifetime trajectory may not suit, nor be possible, for all individuals with

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disabilities. Whereas for some, change is a dreaded condition to be avoided, for others, the prospect of change is a welcome adventure. It all depends on the individual. As we navigate our way to finding good homes, we'll be best served, I think, by those agencies that have flexible models to accommodate our young adults as their lifestyles, goals and aspirations change.



The Eligibility Conundrum

As I said before, the grim reality is that despite the variety of programs to choose from, there may be neither openings nor funding to help transitioning youth find work and daytime activities, or to place them in suitable and desirable settings.

The governor and the state legislature fund the [Governor's Transitioning Youth Initiative](#) program in the state budget each fiscal year, which runs from July 1 through June 30. GTYI funds are presently available in the Maryland state budget for those students with a developmental disability who will exit the school system in fiscal year 2008 at age 21 and transition from school to work. Whether or not GTYI funds will be set-aside for fiscal 2009 will be determined in the next budget cycle. Remember that once individuals have received GTYI funds, they can expect funding for supported employment or day services to continue indefinitely.

For other state-run programs, the figures are sobering. There are currently over 16,000 people on the [DDA](#) waiting list for services. Among these, nearly 40% or 11,626 service requests are in the crisis emergency—crisis resolution or crisis prevention—categories. The fiscal 2008 budget only has funding for 76 people

in crisis and another 60 people not in crisis but needing services. To give some idea of the sums involved, DDA's budget for transitioning youth for 2008—to serve 550 transitioning youth in day supported or day employment—is approximately \$7.6 million. The figure for substantially reducing, not to mention eliminating the waiting list, would be considerably higher. (Go to www.endthewaitnow.com and to www.md-council.org for more information on efforts to make the waiting list a funding priority.)

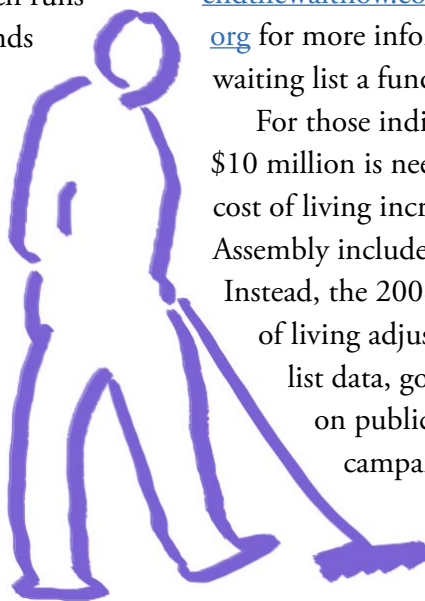
For those individuals who *are* being funded, \$10 million is needed to fully fund the 3.87% cost of living increase that the Maryland General Assembly included in legislation last year.

Instead, the 2008 budget includes a 2% cost of living adjustment.⁵ (For detailed waiting list data, go to www.thearcmd.org, click on public policy, then on waiting list campaign.) The snag is that the

State of Maryland is facing a budget shortfall of almost \$1.5 billion next year. This

does not augur well for the state's health and welfare programs.

On the positive side, in fiscal year 2007, the Community Pathways waiver was approved to serve 10,688 people in the State of Maryland, among whom 1,000 reside in Montgomery

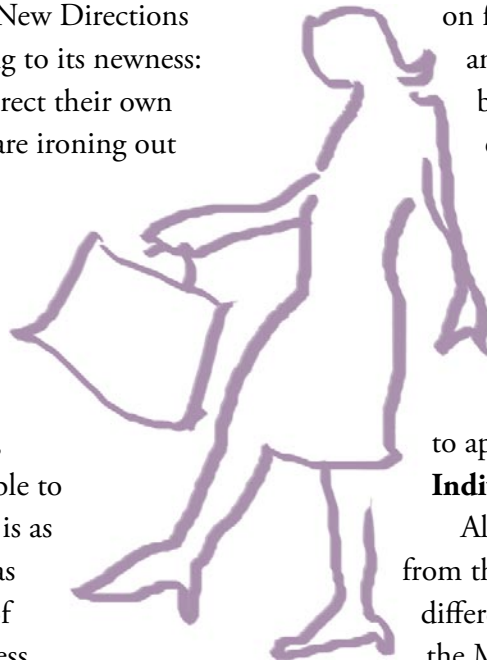


⁵ Larry Carson, *Baltimore Sun*, 18 February 2007.

County. In the same fiscal year, the New Directions waiver was approved to serve 200 people. Five individuals are currently enrolled in Montgomery County. The New Directions waiver is purposely small owing to its newness: families that have elected to direct their own programs are innovators who are ironing out kinks in this waiver program.

When openings do arise, those people who are placed are those in greatest need—those living in dangerous circumstances, or whose medical condition demands it, or whose family is simply unable to care for them any longer. This is as it should be. Even so, as long as demand outstrips the supply of available placements, the process of transitioning young adults so that they can achieve greater degrees of independence—or supporting older individuals who languish while waiting for new opportunities to open up—may be prolonged and difficult for families that have already struggled with enormous challenges for a very long time.

Approximately 16,356 people are presently on the waiting list for services in Maryland (2,620 in Montgomery County), but DDA **Rolling Access** funds are available for low intensity support. Each DDA regional office (there are four in Maryland) distributes *Rolling Access* funds as widely as possible to families in need by way of local agencies, which act as service providers or fiscal intermediaries. There are no low overhead costs and there is no waiting list. Families have been funded on a first-come, first-served basis in the past, but increasingly agencies are evaluating funding on the basis of need. No



family can receive services in excess of \$3000 per year and usually the distributed sums are lower than that. For example, the money can be spent on family support services, respite care, and therapies that are not covered by insurance. To take just one example, DDA's *Rolling Access* grants fund *Bello Machré's* Ray of Hope program, which helps families with therapeutic and camping services, or funding needed equipment, among other things. Individuals over 21 years old are also eligible to apply for *Rolling Access* funds through **Individual Support Services (ISS)**.

Also, there is some solace to be had from the fact that there are so many different service providers—as the list of the Maryland Association of Community Services (MACS) members attests—whose mission is to help families in one way or another. Indeed, just about every MACS member agency welcomes and encourages the participation of volunteers in their programs.

There are also community groups that offer all sorts of programs for adults with disabilities. *Potomac Community Resources (PCR)* (www.pcr-inc.org/) is just one example of an organization that “encourages and supports the integration of persons with developmental differences into the life of the community” by offering, among other things, sports, music and arts programs. Moreover, *PCR* has become a vehicle for attracting people in the wider community to volunteer and become involved with our disabled fellows. *Artstream*, is a relatively new non-profit in the Washington, DC metro area, whose mission is to “create artistic opportunities for individual in communities traditionally underserved by the

There is some solace to be had from the fact that there are so many different service providers

arts” (www.art-stream.org) and has, like *PCR*, generated a lot of interest in the community and attracted new volunteers to become involved in its programs.

A final note: if an individual is on the DDA waiting list and not receiving services, it may be possible for that individual’s family to contract and pay one of the DDA licensed agencies privately for services. For example, in Montgomery County the DDA’s day habilitation

and supported employment rates range from \$42.60 to \$83.00 per day, depending on the individual’s needs. The annual cost per family would depend on the per diem rate for the individual multiplied by 251 work days in the year. So, for example, if a person’s rate were \$50 a day, a family would have to spend \$12,550 for a year of support. Families would have to contact agencies directly and negotiate the terms of such an arrangement.



Things for Families to Consider When Looking for Services

For those who are lucky enough to expect to be funded in one of Maryland's waiver programs, it's worth keeping in mind a number of things in choosing between them.

First, the [DDA](#) financial contribution to an agency—if you choose Community Pathways—or to the FMS agent—if you choose the New Directions waiver—is not an enormous sum of money.

At this point in time, agencies receive approximately \$15,000 annually for an individual's participation in a day program—the average cost per person for DDA day services in Montgomery County—though this figure of course will vary depending on the population being served. Licensed agencies often have to supplement state and federal funds with money they raise if they are to hire qualified and resourceful people to work with their clients.

One of the big problems agencies face is high turnover among employees, owing in part to low wages, but also to the fact that this is very demanding work. We parents know that working with our children may not often be intellectually taxing, but it is emotionally and physically demanding. Agencies

hire and fire their service staff to different degrees depending on the circumstances. Families need to consider what effect continually changing support staff will have on their adult child. The New Directions waiver finesses these issues by giving the individual the opportunity to set hourly rates (within her given budget) and to choose the people who will work with her, and who, it is hoped, will commit to working with her for a long time.

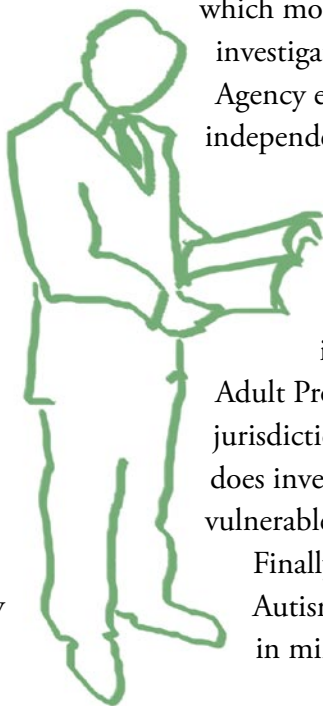
Also, families should consider the fact that all DDA licensed agencies are monitored by the [Office of Health Care Quality \(OHCQ\)](#), which monitors the services provided and investigates any incidents that may arise.

Agency employees are thus subject to regular, independent reviews and evaluations. There is no

comparable oversight of people who are hired by individuals under the New Directions waiver program because the OHCQ does not monitor individuals' or families' private homes.

Adult Protective Services has no regulatory jurisdiction over those employees, although it does investigate reports of neglect or abuse of vulnerable adults in the community.

Finally, for parents of individuals with Autism Spectrum Disorders (ASD), keep in mind that there are agencies that are not



well acquainted with the particularities of ASD. In some cases, agencies take on ASD clients, but fail to provide needed supports because they misjudge the level of supervision that they require; alternatively, some that do appreciate what is required refuse to take these clients on because it is more cost effective for them to take on less demanding individuals given the fixed sum of money they receive.

These are the kinds of considerations to keep in mind when visiting agencies and interviewing supervisors and staff in weighing up the relative merits of each waiver program. Each agency has something distinct to offer families and the only way to discover that is to visit them yourselves, observe the clients they serve and interview the people who run them.

One final thought:

Angela Rapp Kennedy, formerly at the DDA in Maryland, made the observation in a DDA sponsored workshop in January 2007, that in the USA, if you are an adult, you work. Work, she argued simply, enhances life. It establishes competencies, contributes to economic well being and opportunities for career advancement and upward mobility, and it provides social connections for workers. Parents should insist, she stressed, that employment be the first priority for our young adults, even for those in day services.

Parents must create a presumption of employability. It is not a pipe dream, not if families and schools continue to expand self determination training and work to ensure that when our children leave school they have a paid

job. Insisting that work be the paramount goal may also change the balance of accounts: currently, only about 15% of waiver money is used in supported employment.

Somewhere in between business ownership, full-time competitive employment, full-time supported employment, and sheltered workshops is the idea of “meaningful days”—an individualized schedule that could include part-time work, volunteerism, education or training, recreational activities, or other engaging activities that are defined by individuals and assist them

in reaching their goals.

Some individuals on the New Directions waiver are using its flexibility to create days in which they can volunteer at a library, take an art class, go to the gym, and so forth.

For individuals who can't find full-time competitive

or supported employment, a mix of activities designed by the individual to assist them in reaching their employment and life goals may truly be the best alternative. Such a blend of work and activities is also possible through the Community Pathways waiver, depending on the agency a family chooses.

Of course, because not all individuals are alike, goals vary accordingly. For some, full time work is both desirable and achievable; for others, some combination of work and other activities is a better blend. The key to finding the right balance—whether in the realm of work or living arrangements—will depend on weighing up individual needs, capacities, opportunities and aspirations.

Somewhere in between business ownership, full-time competitive employment, full-time supported employment, and sheltered workshops is the idea of “meaningful days”

Epilogue

When I imagine the future for my son Alex, the picture I have in mind is somewhat impressionistic. I haven't begun to grapple with the question of where he will live yet. Instead, I've focused on what he will *do* when he exits school.

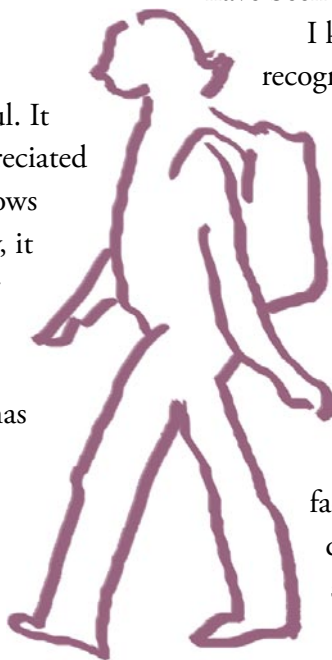
I would like to see him doing valuable full-time work, five days a week, for about 8 hours a day. I would like him to *earn* his leisure time, knowing that he has made useful contributions wherever he happens to be applying his energies. It does not matter too much to me whether the scenario entails that he have 5 separate jobs, 5 days a week, or whether he holds just one, or perhaps some combination of the two. Nor, at this point, does it matter to me that he earn a living wage.

What does matter to me is that the work be important, necessary and useful. It also matters to me that his work is appreciated by colleagues and bosses, so that he knows that his presence is truly valued. Finally, it is important that he likes the work—or if he doesn't much care for it, that he recognizes that it must still be done, and is fulfilled knowing that he has accomplished it well.

It also matters to me that Alex should continue to grow and mature, develop new skills and abilities, and be challenged to do so. In his

case, working with me weekends for the past year at the [Bethesda Food Co-op](#) has required him to generalize skills from school: he has had to discipline himself to sustain focus in that job, often for over 2 hours at a time; he has had to call upon his reading skills and his ability to discriminate among objects, in order to unpack, sort and shelve the scores of items that are sold in grocery stores, and he has had to learn to ask me, or his new colleagues at the Coop, for help and direction when necessary. This is challenging work for him. Each time he has left, the managers have thanked him fulsomely for his valuable help. If he hadn't been there, they stress, their load would have been heavier. There's no doubt about it.

I know, and I think most people recognize, that this is the kind of work that will always need doing. Yet there is a strong negative prejudice among families of young adults with developmental disabilities against the kinds of work that our children are steered towards. The list is referred to derogatorily, derisively, as the *Five F's*: food, filth, folding, flowers and factories, although factories have been displaced by filing, doubtless reflecting our shift to a service economy. I don't understand the prejudice, particularly if work in



any one of those domains suits the interests and capacities of the person doing it, and even stretches him to perform that job to a high standard. For young adults who have special talents that teams of teachers and placement specialists have failed to see, it is incumbent upon parents to share that information, and dream up possible connections with employers to create meaningful opportunities for them.

What I have learned in my time with Alex is that the best outcomes arise when I am fully involved, engaged with and in open communication with the teams of people that work with him. That he has not “normalized” and developed into a “typically developing child” is a long abandoned disappointment. I no longer have dreams of him as a rocket scientist, if I ever did. There are no perfect children, no perfect schools, no perfect jobs, and no perfect lives. There are simply lives—imperfect and full of

For young adults who have special talents that teams of teachers and placement specialists have failed to see, it is incumbent upon parents to share that information, and dream up possible connections with employers to create meaningful opportunities for them.

struggles to be sure—but vested with meaning and value. Our children deserve no less. Whether working in a garden center, keeping a hotel laundry humming, tending horses, mulching trees, cleaning fitness equipment, working with wood, filing documents for insurance companies, entertaining Alzheimer’s patients or shelving books in a library, their lives are meaningful, productive and valuable, certainly to their families and no less to the broader community among whom they live.

The job remains for us all—parents, teachers, transition specialists, job supporters, professionals, friends and so on—to enlarge the circles of teams that support our children and to allow them to overlap with one another so that we may develop an ever larger web of connections that create community and buoy us all.

Additional Sources

- The **Maryland Interagency Transition Council**, composed of 11 state agencies plus nine at-large representatives, meets several times a year to discuss, and recommend changes and improvements to existing programs and policies. For current information on transition resources for Maryland residents, go to www.mdtransition.org.
- *Life Journey Through Autism: A Guide For Transition to Adulthood*, by Danya International, Inc. Go to www.autismcenter.org for more information. This useful brochure is available for free.
- *Transitioning Youth Handbook: Navigating Developmental Disabilities Administration Service System (2004)* Go to www.ddamaryland.org to download a copy.
- *The Changing Face of Benefits: Knowledge for Successful Employment “A Workshop for Self-Advocates, Family and Friends”* This is an excellent resource that explains how recipients of SSI support can change jobs, and earn larger incomes, without necessarily jeopardizing their SSI payments. Sharon Brent, Project Trainer, sbrent@ncbdc.org, 202-336-7689, for details. Cf. also the *Social Security 2006 Red Book* at www.socialsecurity.gov.
- The **Youth with Disabilities Project** is a partnership among **Montgomery Works** (www.montgomeryworks.com), **TransCen, Inc.**, (www.transcen.org) and **Montgomery County Public Schools** (www.montgomeryschoolsmd.org) to provide youth with disabilities still in school with new skills, work experience and job opportunities. See their web sites.
- **OSERS**—The **Office of Special Education and Rehabilitation Services** (www.ed.gov/about/offices/list/osers/index) has a revised guide, *Disability Employment 101 For Your Business* that includes information on what businesses have done to integrate people with disabilities into the workforce, information on Department funded vocational and rehabilitation agencies, **Disability and Technical Assistance Centers** (www.adata.org, 800-949-4232) (DBTACs) and **Centers for Independent Living** (www.ilru.org/html/publications/directory) (CILs). It also includes checklists and other resources to aid employers as they prepare to employ people with disabilities. Get the guide at www.ed.gov/about/offices/list/osers/products/employmentguide/index.html.
- For federal internship and employment opportunities go to www.makingthedifference.org/index.shtml. *Call to Serve*, a joint initiative between the Partnership for Public Service and the **U.S. Office of Personnel Management (OPM)**, is dedicated to helping you learn more about careers in the federal government. To date, more than 575 campuses and 60 federal agencies have joined together to form the *Call to Serve* Network.
- For college options for students with intellectual disabilities, go to www.transitiontocollege.net.

Glossary of Acronyms

ALU—alternative living units

ASD—Autism Spectrum Disorders

CMS—Centers for Medicare and Medicaid Services

CP—Community Pathways waiver program

CRP—Community Rehabilitation Programs

CSLA—community-supported living arrangements

DDA—Developmental Disabilities Administration

DHMH—Maryland Department of Health and Mental Hygiene

DORS—Division of Rehabilitation Services

DT—Discretionary Trust

ESY—Extended School Year

FMS—Fiscal Management Services

GTYI—Governor’s Transitioning Youth Initiative

HCBS—Medicaid Home and Community-Based Service Waiver

ICF/MR—Intermediate Care Facility for the Mentally Retarded

IEP—Individualized Education Plan

IF&B—Individual Plan and Budget

IPE—Individualized Plan for Employment

IP—Individual Plan

ISS—individual Support Services

JFGH—Jewish Foundation for Group Homes

MACS—Maryland Association of Community Services

MA—Medical Assistance

MDETC—Maryland Disability Employment Tax Credit

ND—New Directions waiver program

OBVS—Office for Blindness and Vision Services

OHCQ—Office of Health Care Quality

PCR—Potomac Community Resources

RISE—Reach Independence Through Self-Employment

SNT—Supplemental Needs Trust

SSI—Supplemental Security Income

WTC—Workforce and Technology Center

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