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DO-IT-YOURSELF CASE MANAGEMENT AND ADVOCACY

How to Get Mental Health and Related Services from the Adult System and Things to Do While You Wait

This is a work in progress and the Bureau of Prevention Treatment and Recovery welcomes your suggestions about statewide resources. Address your comments to Marie Danforth, 1 W. Wilson St., R. 951, Madison, WI 53707-7851, call 608-266-2861,

or e-mail marie.danforth@wisconsin.gov

This document can be down loaded from:
http://www.wicollaborative.org/links.htm#Transition.

This paper is a product of the Wisconsin Mental Health Transition Advisory Council, based primarily on work done by Constance Tenhawks, MS, LPC

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Dear Teen, Parent, Teacher, or Service Provider,

What is case management and why do young people need it?

A good case manager functions as a "general contractor" for services – finding the right ones, helping to complete required paperwork, arranging meetings, and trying to get the various providers to work together as a team. You (or your young adult) may have had a case manager in the child/adolescent system, but that case manager generally can't work with someone after they turn 18. The time has come when you may have to "do it yourself".

You probably have been told about waiting lists for services; that does not mean there is nothing you can do in the meantime! We hope this paper can guide young adults and families to what can be done to get services or assistance. The help of parents or caring adults can make a big difference, so try to work together. Figuring out where to look, what to do, and with whom to talk saves time and frustration – just like a general contractor can.

Transition from childhood to adulthood really does not have a start date like the day you turn 18 or graduate from high school or leave home. It's a process with unclear and confusing expectations and time lines for both parents and young adults; the time from 18 to early twenties can be really rocky. If you or your young adult needs services, the situation can be further complicated by a lack of resources in the community, money issues, emotional challenges, family stressors, etc.

Most people who know only the children's system are surprised to discover what the adult mental health system is like. The adult system will expect you or your youth to provide for him or herself to a much greater extent than the children's system did – at 18, services can fall away to be replaced by little to nothing. The entitlement element in children's services just isn't present; eligibility, not entitlement, is the key to adult service doors.

What makes someone eligible? Many things factor in, such as mental health diagnosis, the degree to which a person's ability to function in the community, home, work, school, etc. is impaired, and other considerations. Clients with severe and persistent mental illness usually get top priority for services. If you or your young adult has been diagnosed with a personality disorder or anything other than a major mental illness, chances are you will find quite limited county services. This may even be true if you or your youth has a major mental illness diagnosis. What can you do? It helps if the parents and/or the youth advocate in a determined manner, but there are no easy answers.

Please use this paper as a resource to help guide you to and through the main areas of needed services. Remember: *Applying* to your county (or an agency they direct you to) for services is a way for you or your young adult to be identified as *needing* services. Wisconsin has a county-based mental health system and you will need to work with your county. Counties vary regarding the programs and services they offer. Many programs listed in this paper and those in "Transition Resources for Adolescents with Mental and/or Emotional Disorders and Their Families" are based on state or federal programs and can be helpful, but your primary source of services will most likely be your county. If you don't have the Resource Guide, see www.wicollaborative.org/links.htm#Transition .

HOUSING

Housing is one of the most difficult areas in which to find resources. Someone with no rental history usually needs a co-signer. Someone with bad or no references will have a very hard time finding a place to live. You or your young adult will need the first month's (and possibly last month's) rent and a security deposit, usually equal to the amount of the rent. Many landlords want an income level 3 times that of the rent. For example, if the rent on an apartment is $500, the landlord may request an income level of $1,500 a month. Every community – and landlord - will vary as to expectations.

Subsidized housing may be helpful. There are usually two types of subsidized housing assistance available for people who have disabilities (a diagnosed major mental illness is classified as a disability), and cannot afford "regular" housing:

1.) public housing, available in some areas. When your name comes to the top of the waiting list, a specific unit is assigned to you, or
2.) Section 8 housing assistance, which is a voucher system that reduces the rent in privately owned buildings, if it is accepted by the landlord.

Both programs are worth looking into in spite of a wait, which can last several months. Things can move faster – don't give up. Apply for all the programs for which you or your adult child is eligible – the more options the better.

If a young adult remains at home, clear expectations for everyone need to be discussed. Rent? Rules? Privacy? Talk about these, perhaps put them in writing, and see an agreement as flexible and able to change over time as the youth shows themselves responsible, etc.

SCHOOL

It really helps if you or your young adult stays in school to get that high school diploma! Often school is the primary way to connect to a helping system. If you or your youth receives special education services, there should be a clear community transition plan in the IEP (Individual Education Plan) at age 16, sometimes as early as 14. This plan will outline your or your young adult's goals related to ways (courses, part-time employment, etc.) to become increasingly independent and how the school will assist and sometimes PAY. You or your young adult may stay in school until 21 years of age if he/she hasn't graduated, but he/she can also stay on past graduation until 21 to remain connected to school based services. Usually if a student stays until they are 21, days are not spent at the high school but can be "off campus" in some sort of vocational programming, etc.

There are alternative programs if regular high school is not working for you or your child. There are programs to prepare teens for a General Educational Development (GED) or High School Equivalency Diplomas (HSED – Wisconsin's version of the GED). A tutoring program is one excellent way to work toward a GED or HSED while holding a job. If the student is 17 or older, they may access the HSED via a contract between their high school and a technical college; they may also finish testing early (before "their" class, the one they were with in 9th grade) graduates if they get an age waiver. If they don't have a waiver, they can't test before "their" class graduates. However, a new option has been

developed. Quite a few school districts offer the GED Option #2 which allows credit deficient students to use the HSED tests to demonstrate competency and graduate with a traditional high school diploma – in other words, you can test out! See http://www.dpi.wi.gov/alternativeed/index.html. For additional questions, contact Beth Lewis at Beth.Lewis@dpi.wi.gov. Some community technical colleges have classes to help prepare for GED or HSED tests and permit teens to take their courses simultaneously. Contact your closest area technical college for information. You might want to check out the Youth Options Program, which is designed so high school students can take post secondary courses (meaning after high school) while still in high school; see: http://dpi.wi.gov/ged_hsed/index.html (underscore between ged and hsed). That site also has more information about GEDs and HSEDs. If you Google "free on line education in Wisconsin" there are several options for on line education, any grade.

GED programs as a rule do not offer special programming to students with emotional disorders, although testing accommodations can be requested from the Department of Public Instruction. To find out what a technical college might be able to offer, see "Transition Resource for Youth with Mental and/or Emotional Disorders and Their Families", Wisconsin Technical College System, for a listing of Key Contacts. Again, that Guide and this paper are at www.wicollaborative.org/links.htm#Transition – see cover.

Another resource for some students between the ages of 16.9 to 19 years is the Challenge Academy, offered by the Wisconsin National Guard. More information is available at: http://www.ngycp.org/site/state/wi. Students who get in may leave with their HSED or in some cases, school districts will convert the HSED into a traditional high school diploma.

EMERGENCY HOUSING

Sometimes there is a need to get out of the house fast, either at the request of a parent or because the youth wants to leave as soon as possible. There are places in some communities that can be used for short-term transitional housing where the intent is to have you or your young adult move on soon to a more long-term living arrangement. Examples include the Salvation Army, crisis housing, YMCAs, and YWCAs. Older adults may also use these programs so their beds might be full. Call first.

The Wisconsin Community Action Coalition (CAC) has 16 agencies statewide that can help locate basic services. Call 608-244-4422 to find the Coalition nearest you, or see their web site at http://www.wiscap.org. This excellent site includes information about employment, energy assistance, financial assistance, health, legal services, transportation, etc. Warning: CAC is facing big budget cuts.

SOCIAL SECURITY

Supplemental Security Income (SSI) is a government benefit paid to people with disabilities based on financial need. Your financial resources (if 18 or older) determine if you qualify, and there are regulations regarding how much you can earn before your earnings impact your benefits. Medicaid coverage is included with SSI; Wisconsin calls it (Medicaid) Medical Assistance or MA. See the Department of Health Services (DHS)

Pathways Incentive Benefits Counseling section in the Transition Guide, call 1-800-710-9326, ask your DVR counselor, etc. Generally when people work with a Work Incentives Benefits Specialist, they receive more benefits while being able to work/earn more.

As you know, physicians, therapists, psychiatrists, etc. are expensive and almost unaffordable without health insurance. If you or your youth is under 18, primary coverage is through parental insurance, and MA is a secondary source of coverage. When the family does not have insurance that covers a son or daughter, MA becomes the primary source of payment. It can be difficult to find providers who will work for the rate paid by MA so check around.

It won't apply to everyone, but another possibility offered by Social Security is Social Security Disability Insurance (SSDI), a benefit based on either the young "beneficiary" or parents' work history. The benefit amount is based on the wage earner's total income. As with SSI, there are earned income stipulations (limits). Medical Assistance (MA) is not included with SSDI, but you could still be eligible for MA; contact your local human service agency for more information.

To learn about programs, contact your local Social Security Office – the phone number is in the phone book's Government section (blue pages) - and ask for the Employment Support Representative (ESR) to get answers to specific questions about benefits related to working.

There is a way for persons with disabilities, 18 or older, who receive benefits and are employed but do not have health insurance to buy MA coverage: the Medicaid Assistance Purchase Plan or MAPP. More information can be found at:
http://dhs.wisconsin.gov/medicaid/Publications/p-10071.htm

When you or your child starts receiving benefits, a payee may be needed to assist with money management. County payee services are available without charge if you think it is in your or your child's best interest to keep money issues out of family dynamics. Request a county payee from you or your child's Social Security worker. There are many options about payeeship; it is not an "all or nothing" service.

HEALTH INSURANCE

A program that began in 2008 might be helpful - BadgerCare Plus.
Information about eligibility, benefits, etc. can be found at http://access.wi.gov , by calling 1-800-362-3002, or going in person to your county human services department.

BadgerCare Plus is designed to expand access to comprehensive, affordable health care to children, families, and pregnant women in Wisconsin. Some eligible participants will have a premium (cost). Eligible persons include youth under age 19, regardless of income, pregnant women with incomes up to 300% of the federal poverty level (FPL) ($63,599 for a family of 4 – you will need to check, the amount changes over time); parents or relatives caring for a child with incomes up to 200% of FPL ($42,400 for a family of 4 – again you would need to check on current level); or young adults born after Jan 1, 1990 who are aging out of foster care. Also included are farm and other self

employed families with incomes up to 200% - calculation now excludes depreciation - and parents with children in foster care who are working on a reunification plan for their children to return home.

MENTAL HEALTH TREATMENT/MEDICATION

"Talk" therapy is one of several forms of treatment that people find helpful; there are many other options to consider. Mental illness adds stress to everyone in the family, so a family might benefit from being seen together. Insurance companies usually dictate which providers and services are covered (paid for). Without private insurance, you will need to find providers who accept MA/BadgerCare Plus. Many counties have mental health services offered on a sliding scale fee, and your county is the place to start looking. Counseling is sometimes available through high schools or technical/traditional colleges. In many areas of the state, there are other community resources for therapy on a sliding fee scale or that take Medical Assistance. Among these are:

* Catholic Social Services
* Jewish Social Services
* Family Service
* Lutheran Social Services

Many counties also have Crisis Intervention Services – check the yellow pages.

EMPLOYMENT/DVR

Work is therapeutic. It can build self-confidence, teach employment skills and habits, provide experience for future references, etc. Working automatically brings with it adult expectations regarding behaviors and responsibilities. The primary correlation for getting adult employment is employment as a teenager – if a youth had a job as a teen, he/she is more likely to find adult employment. Any paying job is a good start and even volunteer work can build skills and confidence. Once you or your young adult turns 18, work opportunities expand greatly beyond the usual fast food places. High school can be a great resource for finding jobs in the community.

Another good resource for persons with disabilities is the state Division of Vocational Rehabilitation (DVR). If eligible, you or your child will have a counselor who will assist in vocational planning. Do not wait for graduation from high school before connecting with DVR. A vocational component should be prime part of every IEP transition plan, and contact with DVR should be included in it. Sometimes DVR staff can attend an IEP meeting as a "consultant" – they probably can't make every IEP meeting, but attending even one meeting can be helpful.

Another option that not everyone knows about is AmeriCorps, often referred to as the domestic Peace Corps. It gives citizens, at least 17 years of age, a chance to engage in community service in a wide variety of areas such as land conservation, tutoring children and adults, food collection and distribution, etc. People serve for a 9 – 12 month term and receive a small living allowance, health care and child care (if qualified), a possible education award ($) to help pay for college, professional and personal development, and the chance to make a difference in the community. If you want to learn job skills, build a resume, contribute to the community while trying to figure out future goals, and lots of other benefits, AmeriCorps may be for you. For more information about serving with a Wisconsin based AmeriCorps program, go to www.servewisconsin.org and

click on the AmeriCorps Programs link or call 800-620-8307. For opportunities outside Wisconsin, see www.americorps.gov or call 800-942-2677.

SO, WHERE TO START?

A major first step to getting needed services is having a mental health diagnosis. Get yourself or your young adult evaluated to determine an adult diagnosis if you have not already done so. If you or your young adult has serious and persistent major mental illness, seek out long term case management services through your county's Community Support Program (CSP), if your county has one - CST programs are available in over half of Wisconsin counties. Another option may be Comprehensive Community Services (CCS), a community mental health program available in a growing number of counties, providing psychosocial rehabilitation services to individuals of all ages who need more than traditional outpatient services but less than CSP, that is, an ongoing need for comprehensive services for those with either a mental health or substance abuse diagnosis.

You or your youth's therapist, psychiatrist, teacher, or social worker can make a referral to any program that appears appropriate. In a few locations, there are CSP programs that accept adolescents, which can be very helpful. There is no state-mandated minimum age requirement to be part of a CSP – you can try for a pre-eighteen admission or ask to be put on a waiting list.

Developing or encouraging independence is another key issue. Some suggestions:

1. You or your youth may desperately want to be treated as an adult yet you or they do not have a good grasp of what being an adult involves. A parent's most valuable gift to a teen is being an appropriate adult role model. Youth need to be able to seek suggestions or support without fear of ridicule or being steamrolled by parental opinion. Parents can offer support as the decision making process develops – everyone needs practice. Mistakes are great teachers.

2. Teen – do as much of the calling for information, getting forms, completing paperwork whatever is needed – as you can. This is part of getting ready for adult living, and you, logically, are going to be much more willing to get involved in services you find, rather than ones your parents found for you.

3. Start keeping your own records. There is a record keeping suggestion sheet at the end of this booklet, and getting and keeping these records will save everyone lots of time, effort, and money. Be sure to keep a page with the information usually asked on most forms or copy a completed form – you can use it as an example when filling out other forms in the future. There will be lots more forms!

4. Focus on getting and saving money for an independent place to live. For some people that means getting a job, for others, applying for SSI – or doing both.

5. Next, apply for public housing. Even if you (or your son/daughter) is not currently interested in public housing, things may have changed when your or your youth's

name hits the top of the list. (Young people who are in foster care should work through their area's Independent Living Program and/or their worker can help make connections).

6. Make sure your IEP transition plan includes DVR/employment goals. School is often the only link to services so hold on to that connection as long as you can. Also, establish a relationship with a DVR counselor whether DVR is included in your IEP or not, or if you don't have an IEP. DVR can be a valuable help to you.

7. If needed, have a crisis plan worked out through the county mental health department or Crisis Intervention Services. Make sure all those involved with you or your young adult knows the plan and has a copy of it; it should include all important names – like parents, M.D., case worker, etc. - and how to reach them.

8. Try to lead as normal a life as you can. Find and keep healthy friendships and relationships in the community. Both you and your parents need to try to distinguish between disability related behavior and typical child/adolescent behavior – and that is often not easy to do. As an example, are your "blues" temporary or a sign you are seriously depressed? Learn the signs to watch for – maybe even write them down and keep them to refer to in the future. Read about your or your youth's illness. Also, check out http://wwwstrengthofus.org.

9. Remember, adolescence is the time to prepare for adult living, the time to practice – (and for adults to role model/encourage thoughtful decision-making). A good question for young adults to keep in mind is "What am I going to do about that?" or "How am I (not my parents) going to handle that?" You can ask for help brainstorming options and possible consequences, but try to make independent decisions and live with the results. Start small and build up to more important decisions. Life is a wonderful teacher. Maintain optimism; your feelings and behavior at 17 are not how you will feel and behave at 27 and there are many wonderful and interesting experiences ahead.

10. Lastly, a word for parents. Make sure you get lots of support and information for yourself. You know that parenting is hard work and parenting a young adult with mental health issues is tremendously hard work. There is a national organization that supports parents and advocates for changes in the laws concerning mental health issues, among other activities. It is called the National Alliance on Mental Illness (NAMI). The state organization, NAMI-Wisconsin, has an office in Madison with an extensive library and up to date information. It can be a great help finding resources and support groups in your area; there are local chapters around the state. Support from other parents experiencing similar challenges can really help – no one else knows what it is like except another parent who has been through it. The state office toll free number is 800-236-2988, or go to: www.namiwisconsin.org. NAMI publishes a very good resource booklet called "The NAMI Wisconsin Family and Consumer Resource Guide" which you can request.

Best wishes for a successful transition to adult living – it may be a bumpy ride, but you are bound to learn a lot on the journey.

Record Keeping Suggestions

Get a handy size notepad for taking notes, recording names and dates, numbers, etc. Put filled notepads in a file, such as an accordion file folder, along with the following records. A new file for each school year works well. Subdivide with manila folders for:

- Current IEP and team meeting notes, daily/weekly progress reports, contact info;
- Medications: date started, dates of any changes, amount of dosages, side effects, medical test results (such as blood work, if required), contact info, etc. Write down significant changes you notice, positive or negative – for example changes in behavior, appetite, or sleep;
- Test dates and results (psychological, neuropsychological, etc.);
- Crisis Plan, emergency contact people and numbers, who has copies (such as teachers, bus drivers, school nurse, therapist, local police if appropriate). What works? What should be avoided? Try to keep it updated;
- Current Behavior Plan, school and/or home, meetings and/or conversations with teachers and other involved school personnel;
- Team Meeting notes (especially who is to do what); and
- Log of calls regarding insurance, MA, and/or SSI and names of those spoken to, which applications have been completed, and anything else you want.
- Person Called:_____ Agency:_____

  Phone #:_____ Date:_____
  Comment –

- Person Called:_____ Agency:_____

  Phone#:_____ Date:_____
  Comment –

- Person Called:_____ Agency:_____

  Phone #:_____ Date:_____
  Comment:

- Person Called:_____ Agency:_____

  Phone#:_____ Date:_____
  Comment:

- Person Called:_____ Agency:_____

  Phone #:_____ Date:_____
  Comment:

Suggested people to list include police, the case coordinator, etc.

If you are tracking more than one child, try color-coding files to keep each distinct. Try to update/sort every 3 months or more often. Keep this sheet in the front to remind you of the contents and dates you updated it.

Date started:_____

Updated:_____

Updated:_____

Updated:_____

Closed:_____

Recognition goes to former Wisconsin Family Ties' parent advocates Kathryn Jalas Franke and the late Ann Hager for most of these ideas.