

Operation House Call: Tips for practitioners of adult health care from our volunteer families for the BU School of Medicine, Residents' Family Practice rotation 2014-2015

- Build your relationship with both the patient and the parent/caregiver together and separately.
- Develop a good understanding of resources available for the individual patient, and also for the daily caregivers.
- Families often need special documentation of specific disability and disabling conditions for the many applications for community programs, services and public benefits. Timelines are always short for collecting information and submitting periodic verification and assessment forms.
- Build a basic understanding of an individual's access and eligibility for services provided by the state, or privately, and how funding streams (health, public, insurance, private, other). You may be asked to fill in a form to determine eligibility. (Ex: The RIDE)
- Parents have to learn a lot more acronyms in the disability world and use them in shorthand just like medical folks do. Don't be afraid to clarify. Ex: DDS, DMH, MRC, IEP, ISP see explanations in the acronym list below.
- Read an IEP or ISP and pay attention to the modifications and accommodations. There may be a lot of medical/well-being information in this legal document. One can attend an IEP/ISP meeting for a teenager or young adult if you ask, for experience!
- Saying "I don't know" is ok. Better when you can back it up with a referral that makes sense. Not just for more tests or procedures. Have a short list of people - not just organizations - to put patients in touch with for help. You have many "experts" within your patient population. Don't be afraid to connect them to each other for support.
- If your patient is accompanied by a family member or an advocate you must resist the temptation to get your information from the helper. Attempt to get as much information from your patient before resorting to getting an answer second-hand. If you need to get clarification from the helper return your focus to your patient as quickly as possible.
- Try to schedule a longer appointment or at a time more conducive to running over. As a last resort you may need to schedule another visit.
- Have an open mind to the possibility that a condition/disease exists in your patient that is unrelated to their disability.
- Provide the opportunity for a family member/helper to speak with you privately, without individual present, if requested or needed. Use discretion in how you frame this, so that the patient feels it is just your good practice, and not a way to undermine the patient's perspective.

- Greet your patient directly, no matter the disability. Discover the best way to do so. Enlist family member or helper's teaching if you need. Also do this when saying goodbye at the end of the visit.

Acronyms in this document and brief explanation of services:

IEP: Individual Education Plan This is a document of services, frequency and length of service provided by the school district (daily/weekly/monthly) goals and evaluation of goals met, and is for public school aged persons up to age 22. It is developed in a team approach coordinated by a representative in the school's Special Education department along with relevant teachers, therapists, and the family. It is updated yearly, and it is a legal document. Families can reject the IEP. Doctors may be asked to document need for specialized care (allergies, mobility access, transportation needs, sensory needs, etc.). Important note: having an IEP in the public school system does not automatically translate into eligibility for DDS services as an adult. "Transition" for ages 18-22 is the time period in which IEP providers are supposed to address the individual's needs for support as an adult, and guide families to apply appropriately.

DDS: Department of Developmental Services (formerly known as DMR). DDS provides adult services and/or channels funding for services to provider agencies. Individuals need to go through a formal evaluation to be deemed eligible for DDS services. IQ testing higher than 70 in the past has been a benchmark for ineligibility. Massachusetts legislation in 2013 has loosened this requirement. Services can include work/day programs/living supports/recreation support, and etc. as determined by an individual's ISP. Important: determining eligibility is crucial for services but does not guarantee funding. If a family can provide, financially, then DDS will not fund and family will need to pay privately. It is a tiered system, to divide state funds among the most needy.

ISP: Individual Service Plan: This is a document, similar to the IEP, above, but for adults and it outlines an individual's adult DDS services and yearly goals. The ISP is developed by DDS, and reviewed yearly, for all individuals receiving services/funding support. The yearly ISP meeting is attended by the individual receiving services, the individual's DDS case Manager, a family member or guardian if possible, and a representative from each service funded by DDS. Examples of services: Day Habilitation (Day Hab) Program, Work support center, respite, group or independent living support agency.

DMH: Department of Mental Health. Hard to get services from this unless a primary diagnosis of mental illness present but some persons with intellectual disability do receive this funding.

MRC: Mass Rehab Commission. MRC mainly provides a variety of adult vocational and independent assistance programs. Its aim, overall, is to become redundant to the individual and therefore it can be time limited.

The RIDE: Within a prescribed area of Metro Greater Boston, individuals with special transportation difficulties and special needs can apply. A medical reference is required. The RIDE has different levels of care and it can accommodate those who have intellectual/developmental disability. As of 2015 renewal of eligibility is required every three years.