

## Office Organizational Tips – Patients with Developmental Disabilities (DD)

### Pre-Appointment Preparations

#### Primary Care Provider Preparations

- While the focus of relationship building and communication should be on the patient with DD, it is also important to establish a relationship with, and obtain information from, the patient's main caregivers (e.g., family, group home staff and manager).
- Consider inviting caregivers who know the patient well to come for a pre-appointment visit. Provide them with the Caregiver's Health Assessment tool prior to the first visit so that they can complete as much as possible prior to the appointment.
- Explain to caregivers the importance of ensuring that the person who accompanies the patient with DD is reliable and familiar with the patient's current health issues.
- Try to alleviate the anxiety of the patient with DD by asking caregivers to bring to the appointment a familiar and comforting object from home (e.g., music, book).

#### General Office Preparations

- Meet with office staff to discuss office organization and accommodations for visits by specific patients with DD.
- Assess the physical access to the office and equipment required prior to the appointment.
- Check accommodations that may need to be made (e.g., for some patients with autism, taking off one's glasses may be important, or for patients with pica, removing objects from the waiting and examining rooms that could be eaten).
- For patients with DD who are quite anxious about visits to the doctor:
  - Have patients visit the office at least once and, if possible, two to three times, to acclimatize themselves to the office and for an introductory 'meet and greet' session. Such initial visits should only involve meeting staff and getting used to sounds and smells (i.e., no examinations or treatments).
  - Encourage caregivers to drop in with patients with DD to allow them to become familiar with the environment.
- Reduce stress by respecting the patient with DD's limits (i.e., it may take several visits to complete a physical exam).
- Take a proactive approach to avoid potential difficulties (e.g., by using rewards or distractions).

## Initial Office Appointment

Allow sufficient time to assess the patient with DD's communication skills and to establish rapport (may need to book a double appointment).

- Be prepared to end an appointment early if it becomes distressing to the patient with DD.
- For patients with autism, book a time for the appointment that least disrupts their daily routines.
- Inform your office staff when a new patient with DD will be arriving. Schedule the visit time to minimize the waiting. Instruct staff to take the patient with DD and caregiver(s) directly to an appropriate room.
- Greet the patient with DD first. Ask whether you may use their first name and whether the caregiver(s) can stay.
- Inform patients with DD that you may later ask whether you can examine them alone.
- Agree on an agenda at the beginning of the visit with all present.

## Follow-up Visits

- It may take a few visits to understand adequately a complicated medical history and to establish mutual trust in order to allow uncomfortable or invasive examinations.
- Corroborate the history with different caregivers involved in the life of the patient (e.g., group home and day program workers), either during office visits and/or through later telephone conference calls.
- Specific advanced preparation and coaching may be necessary for intrusive examinations (e.g., pelvic examinations in women). For further information, see the resources below.

## If exams and investigations are needed

- Ask permission to proceed before any intrusion of the patient with DD's personal space.
- Explain and warn the patient about what to expect from procedures that may need to be done immediately.
- Ask caregivers whether individual care plan or protocols have been established for some procedures (e.g., venipuncture) and follow these.
- Provide reassurance during the procedure.
- For bloodwork, X-rays or physical exams, some patients may require various strategies that may include social stories about this exam, continued reassurance and support, and a desensitization plan.
  - For patients with DD who are resistant to a physical exam, consider gradual repeated exposure to the office and instruments such as the exam table and blood pressure cuff. Eventually, when patients with DD feel safe enough, invite them to lie down on the examination table.
- Use of topical anaesthetics, such as EMLA cream (apply at least one hour before procedure) or a sedative medication, such as lorazepam, may be helpful prior to distressing procedures, such as blood tests and radiological investigations.

## Referrals

- When referring, identify that this is a patient with DD. Send as much information as possible, including any adaptations, accommodations or communications that you have found helpful with this patient (i.e., all the information you would like at a first visit).
- Consider a direct telephone call with the specialists concerned so that they understand the referral question and the complexities that may be faced in evaluating particular patients with DD.
- It may be helpful to network with other physicians in your area who care for patients with DD. They may know and have worked with specialists who are especially accommodating and knowledgeable regarding patients with DD.
- If a referral is made for a specialist consultation, consider deferring blood tests until after the appointment so that all tests can be undertaken at one time.
- Keep track of referrals made until consultation reports are received.

## Prescriptions

- Send a copy of any new prescription to the patient with DD's pharmacist, maintain a copy on the chart, and provide the patient or caregiver with a copy.

## Resources

Autism Steering Committee – North Shore LIJ. *Your next patient has autism*, and other resources regarding autism spectrum disorders for health care professionals. [www.northshorelij.com/NSLIJ/autismtoolkit](http://www.northshorelij.com/NSLIJ/autismtoolkit)

Simpson, KM. Table Manners and Beyond – The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations. [www.bhawd.org/sitefiles/TblMrs/cover.html](http://www.bhawd.org/sitefiles/TblMrs/cover.html)

Witemayer S. Gyn Exam and Mammograms for Women with DD's. – Recommendations for routine gynecologic examinations and mammograms for women diagnosed with DD's. <http://hsc.unm.edu/som/coc/resources/articles/GYN.pdf>

## References

1. Bradley E, Lofchy J. Learning disability in the accident and emergency department. *Advances in Psychiatric Treatment* 2005;11:45-57.
2. Lennox N, Beange H, Davis R, Survasula L, Edwards N, Graves P et al. Developmental Disability Steering Group. Management Guidelines: Developmental Disability. 2005. Version 2 Therapeutic Guidelines Limited, Victoria, Australia pp. 7-27.