CASE THREE

James Foster is a 22 year old man who has had a severe cough for over a week. Until 6 months ago he lived with his parents in a city housing project, but his parents turned him out of the apartment. He has been living on the streets and in and out of shelters since then. His family has always lived in poverty; his parents are both unemployed. Mr. Foster has ASD, a mild intellectual disability and a diagnosed anxiety disorder. A case worker from the local homeless shelter has told him he can’t stay at the shelter until he is seen for evaluation of his cough. He tells the case worker that he doesn’t have a regular doctor so the case worker takes him to the County Hospital’s Emergency Room.

**Question 3.1**
Given Mr. Foster’s disabilities, would you expect that he has services and supports? Is it surprising that he is homeless?

**Answer 3.1 and Related Resources**

Generally, an individual with Mr. Foster’s disabilities may be eligible for a variety of services and supports, including special education and related services through age 21. If he had been enrolled in special education, a transition plan to prepare him for adult living may have been developed and implemented. He might also be eligible for state developmental disabilities services, SSI, and Medicaid for health care. However, even if he is connected to services, he may not have housing supports. Over 75% of people with ID in the United States live with families, and more than 25% of family care providers are over the age of 60 years and another 38% are between 41-59 years. (Braddock D, Hemp R, & Rizzolo MC. *The state of the states in developmental disabilities: 2008.* Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.) The fact that his family situation appears to be unstable, makes it more likely that he is not connected to services and supports, including housing. Living in poverty has likely impacted on his current status. Children and adults with intellectual disabilities are more likely than those without disabilities to live in poverty. This association is multifacteted. Poverty in childhood increases the likelihood of a developmental disability. Costs associated with needed services and supports (health and others) can increase the chance of becoming poor and decrease the ability to escape from poverty. Having a disability increases exclusion from the workforce, exacerbating poverty.

Because individuals with ASD may have challenges with social interactions generally, they may be less comfortable living with other people and less likely to avail themselves of available social services. The noise, smells, and number of people in congregate living situations may be untenable for someone with ASD like Mr. Foster. Although there is little reliable data available on the adult homeless ASD population, it is believed that a large number of undiagnosed individuals with ASD...
are homeless.

Below-average intellectual functioning has been identified as a risk factor for homelessness and a predisposing factor for vulnerability among street people. Most homeless adults with ID attribute their homelessness to substance abuse, mental health problems, and fractured relations with family. [Mercier C, Picard S. Intellectual disability and homelessness. Journal of Intellectual Disability Research. 2011; 55: 441-9.]

Additional References/Resources:


- Braddock D, Emerson E, FelceD&Stancliffe RJ. Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. Mental retardation and developmental disabilities research reviews.2001;7: 115–121

- http://www.autismspeaks.org/family-services/housing-and-residential-supports


**Question 3.2**

**What could be barriers or challenges to providing care for Mr. Foster in the emergency department setting? How could these challenges be overcome?**

**Answer 3.2 and Related Resources**

Most patients find waiting to be seen in a busy emergency department both frustrating and anxiety producing. Surrounded by other ill people, being subjected to long waits, and seeing health providers who are not familiar with their health history, is not the best formula for a good health care experience. These inherent problems in emergency room care may be magnified for someone like Mr. Foster. Adults with ASD may have one or more of the following characteristics which could impact the health care experience: impaired social skills; impaired verbal and nonverbal communication skills; limited coping skills to deal with distress, resistance to environmental change or change in daily routines; gaps in intellectual development; labile mood; and unusual responses to sensory experiences. Mr. Foster’s ASD and other disabilities may present unique challenges in this already difficult emergency room environment. In addition, because he is not accompanied by a family member or caregiver who knows his strengths and challenges, the ER staff will have to rely on their own training and experiences to provide an accessible health care visit.
Since emergency room personnel often provide care to people with ID, it is important for them to be specifically trained in communicating with and providing care for people with ID. However, ER staff do not always receive specific training in this area. Asking Mr. Foster what he needs is the first step for making the visit successful. He may be able to guide the staff by telling them what works and what doesn’t for him in this highly-stimulating environment. Providing a quiet separate space for him to wait may help to reduce his anxiety. Personnel should explain in detail what is going to happen during the visit and limit the number of times he is asked to repeat his story. It is helpful to offer the use of visual supports to determine if they will assist him in the communication of history or needs. A short summary of the use of visual supports is provided at http://www.autismspeaks.org/docs/sciencedocs/atn/visual_supports.pdf

Healthcare providers should also be aware that persons with ASD may perceive sensations of touch, hearing, smell, and taste very differently than others. Some individuals may demonstrate a higher tolerance for pain, while at the same time finding a “light” touch or loud sounds intolerable. It is important for healthcare providers to consider what examination modifications may be necessary for a patient with sensory sensitivity as well as refraining from unnecessarily touching a patient.

Recent changes in health care law as part of the Affordable Care Act make it more likely that in the future emergency room personnel may have access to previous medical history of a patient, through state Health Information Exchanges. These electronic data systems will allow, with the patient’s consent, for previous medical records from other providers to be viewed during an emergency room or other health care visit. In addition, more individuals with IDD are creating their own personal health records on-line or creating health care notebooks to help inform new health care providers of their conditions, medications, and social history. An example of this kind of tool may be found at: My Health Passport, http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

Case Continuation: The shelter case worker tells the receptionist in the Emergency Department that Mr. Foster doesn’t have his insurance card and will need help with the paperwork and then she leaves. A hospital social worker is called to work with him to fill out the medical and social history and determine if he may be eligible for or already enrolled in Medicaid. He is able to answer her questions. He tells her he hasn’t seen a doctor in many years and doesn’t know whether he is on Medicaid, though he thinks he might be. He knows he gets a “disability check” but since he left his parents’ apartment he doesn’t know what has happened to the check. He says he has no job and didn’t finish high school. He seems reluctant to talk about his parents and becomes very agitated when the social worker asks if she can call them or some other family member or friend to let them know he is in the ER, but he does mention an aunt he feels comfortable with who lives in town. The
social worker asks him if he receives Social Security Supplemental Income (SSI) and he reports that he thinks he does but he has not recently received a check.

**Question 3.3**
How does Mr. Foster’s family situation and employment status impact his access to health care and other services?

<table>
<thead>
<tr>
<th>Answer 3.3 and Related Resources</th>
</tr>
</thead>
</table>
| A support network is important to the success of any young adult. Many adults with IDD receive help from their family in obtaining benefits, accessing health care, and advocating for services. In addition to providing a home and food, many families may also provide transportation for their adult child with IDD. In the current situation, Mr. Foster’s parents seem unable to provide support to him or perhaps even to take care of themselves.  

Adults with IDD with little or no work history may be are eligible to receive a monthly payment called Social Security Supplemental Income or SSI. This requires a finding that the individual is unable to perform substantial gainful activity ([http://www.ssa.gov/pubs/EN-05-10029.pdf](http://www.ssa.gov/pubs/EN-05-10029.pdf)). The SSI benefit amount varies because some states supplement the federal amount. The monthly maximum Federal amounts for 2013 are $710 for an eligible individual.  

Mr. Foster believes he was at one time receiving SSI. This presents a concern that his family may be receiving his SSI or “disability check” and not utilizing it for Mr. Foster’s living expenses and assistance. The social worker should investigate whether he is on SSI and where his SSI check is deposited. If he is unable to handle his own funds, he may need a representative payee appointed. A representative payee is an individual or organization who will receive SSI check and distribute amounts as needed to help him meet his monthly expenses and provide him with spending money. Additional information is available at:  

It is possible that Mr. Foster maybe able to participate in the workforce. Meaningful work is important to individuals with IDD and can contribute to health, wellness and increased self-worth. He may not have had access to information about opportunities for competitive employment, post-secondary training or education leading to employment. People with IDD who receive SSI may have been told that are unable to work, or that they may risk losing benefits if the work. Mr. Foster may benefit from working with a trained vocational counselor and a benefits counselor to explore employment options available to him and assist him to make choices based on his interests, talents, and work related skills. The social worker may be able to connect him with both the local DD Service Agency and the Vocational Rehabilitation Agency where the process will begin. |
Question 3.4

Is it unusual that Mr. Foster does not have a primary care provider (PCP)? What are possible barriers to his finding a PCP?

Answer 3.4 and Related Resources

Like many adults with ID, Mr. Foster does not have a PCP. Once study noted that people with ID often must contact many physicians before they can find one who will provide care to them. (http://www.specialolympics.org/uploadedFiles/EIC-SOI%20report.pdf)

Few adult health primary care providers are trained in the health care needs of adults with ID. There is also a perception that a visit with a patient with ID will take more time. With pressures in the typical primary care practice to limit the duration of patient visits, many PCPs do not want to take on patients with disabilities.

Recently, some health professions education and training programs have added content on providing care for adults with ID. The American Academy of Developmental Medicine and Dentistry, AADMD, and other professional and disability organizations are addressing the education and training needs of professionals to enable them to skillfully provide health care for adults with ID. Some family medicine and internal medicine residency programs now include curriculum on primary care for people with ID and on common health concerns related to specific disabilities, including curriculum concerning preventive and wellness strategies.

The Nisonger Center UCEDD at The Ohio State University provides on-line training for health professions trainees and health professionals (Healthcare Access for Persons with Disabilities). The training has the following learning objectives: define disabilities, particularly developmental disabilities; summarize the Americans with Disabilities Act, Developmental Disabilities & Bill of Rights Act of 2000, and the Rehabilitation Act; identify common developmental disabilities and associated secondary conditions; list barriers to quality healthcare for people with disabilities; develop a minimum of five skills to increase good communication and rapport to enhance accurate assessment and delivery of quality care for patients with developmental disabilities. This training is available at (with pre-test and post-test) at: http://nisonger.osu.edu/disabilityconted2.htm

Question 3.5

What should the social worker do to connect Mr. Foster to services and supports?

Answer 3.5 and Related Resources

The social worker could investigate whether he may be eligible for the following services and supports: Developmental Disabilities Services (which could include employment related services, housing, therapies, case management/service coordination); Behavioral Health System Services (medication, counseling, housing, employment services); Vocational Rehabilitation (job training and related supports); Transportation (either through paratransit or training to ride the public transit system); Subsidized Housing (through City Section 8, Public Housing, and voucher...
programs); Medicaid (Health care); and SSI (financial support).

It is unlikely that a hospital social worker will be able to do more than determine his current eligibility and connect him to these systems. These complex systems may be very difficult for him to navigate on his own. In order for him to be successful in getting his life on track, he is likely to need an advocate who can help him navigate these systems. A family member, such as his aunt, may be able to help. Some communities have patient navigators as part of the service system or Developmental Disability Services. Independent living centers or self-advocacy organizations may assist individuals to navigate services and supports.

Case Continuation: Hours later, Mr. Foster is finally seen by an emergency department physician. By this time, he is extremely anxious and has started to pace in the small room and talk to himself. He is also coughing violently and has a temperature of 102 degrees. The physician has reviewed his history and sees that he reports being in generally in good health, except for ongoing gastric distress. He notes that Mr. Foster reports smoking one pack of cigarettes per day. The social worker has written a note across the front of the folder “Warning: Patient Autistic and Anxiety Disorder”. The doctor knocks on the door and walks into the room.

Question 3.6
How should the physician approach Mr. Foster’s examination? Are there methods he can use to lessen his distress?

Answer 3.6 and Related Resources
Anxiety is very common in children and adults with autism spectrum disorders. It is important for all healthcare providers to approach Mr. Foster with calm confidence and to avoid rushing through the interview or exam. Take some time at the beginning of the visit to talk with the patient, adjusting your speech according to what they seem to understand and respond to. It will be helpful to review the steps of the physical exam before beginning and as the exam proceeds. “Now I will look in your ears with this instrument” giving the patient a chance to examine the instrument before it is thrust into his ear. Throughout the encounter, monitor signs of anxiety and adjust your pace and proximity. Encourage the patient to tell you what makes him uncomfortable and what you can do to help.

This issue of the ACP Internist, a publication of the American College of Physicians, outlines an approach to working with adults with ASD:

The University of Toronto’s “Guidelines for Managing the Client with Intellectual Disability in the Emergency Room” is a resource developed to assist psychiatry residents seeing people with ID in the emergency department and has sections that are more broadly applicable to others with ID.
http://knowledgex.camh.net/amhspecialists/specialized_treatment/dual_diagnosis/er_guidelines/Doc
Question 3.7
Should the doctor ask about his tobacco use? Would it be appropriate to counsel him on stopping smoking?

Answer 3.7 and Related Resources

| Tobacco cessation is probably better addressed in the context of a primary care visit. |

Generally, people with disabilities are twice as likely to smoke than people without disabilities although it is thought that the percentage of people with ASD who smoke is much lower. Individuals with ASD may be less likely to be influenced by peer pressure around health risk behaviors including alcohol and tobacco use. Although there has been little research on people with IDD and tobacco use, the data suggest that rates of tobacco use are lower compared to people without disabilities [McGuire B E, Daly P and Smyth F. Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research.* 2007; 51: 497–510.] [Wells M, Turner S, Martin D, & Roy A. Health gain through screening -- coronary heart disease and stroke: developing primary health care services for people with intellectual disability. *Journal Of Intellectual & Developmental Disability.* 1997; 22(4): 251-263.]

Smoking rates may be higher for adults with IDD who live independently and, therefore, have greater access to tobacco and more control over tobacco use [Tracy J & Hosken R. The importance of smoking education and preventative health strategies for people with intellectual disability. *Journal of Intellectual Disability Research.* 1997; 41:416-421]. Although smoking rates may be lower in adults with ASD, smoking is endemic to homelessness with approximately 75% of the homeless population using tobacco [Baggett TP, Rigotti NA. Cigarette smoking and advice to quit in a national sample of homeless adults. *American Journal of Preventive Medicine.* 2010; 39: 164-72.]

Few tobacco cessation interventions have targeted people with IDD. Health care providers are less likely to address tobacco use with their patients with disabilities. Provider perceptions that people with disabilities have “enough to deal with” without quitting smoking or that they are “unhealthy anyway” because of a disability prevent them from intervening in a positive way regarding IDD patients tobacco use. People with IDD and other disabilities experience health disparities and a variety of preventable secondary health conditions including obesity, high blood pressure, heart disease and diabetes. [Centers for Disease Control and Prevention. “Current Cigarette Smoking Among Adults — United States, 2011”. *MMWR.* 2012; 61:889-894.
http://www.cdc.gov/mmwr/pdf/wk/mm6144.pdf.]

It is likely that, once his life stabilizes, he would benefit from a health education program to help him understand the health implications of smoking and to better understand his own smoking habits.
habits. It will be important to offer support in quitting if he decides to do so.

A primary health care professional will be able help Mr. Foster choose strategies for quitting smoking. These strategies may include in developing a quit plan in collaboration with their caregivers or families. Health care professionals could also help him explore appropriate medicines to help with nicotine withdrawal. Some services to help people quit smoking are covered under the Affordable Care Act. Depending on Mr. Foster’s insurance plan, he may be able to get these services at no cost. The social worker could check with his insurance provider to find out what tobacco cessation strategies are included in his plan.

Additional Resources:

- Everyone Has the Right to Be Healthy: Information for people with disabilities and their caregivers on how to quit tobacco [http://www.midisabilityhealth.org/documents/Tobacco_brochure.pdf]

Case Continuation: The doctor is able to conduct a limited examination and concludes that Mr. Foster has the flu. He recommends a warm place to sleep and proper nutrition in order to recover. He also recommends a follow up appointment at a primary care clinic affiliated with the County Hospital.

The hospital social worker was able to check with the state Medicaid office and found that Mr. Foster was previously eligible for Medicaid, but had failed to re-enroll. She has started the paperwork to reenroll him in the Medicaid health care system. She has also put calls in to both the state developmental disabilities system and the local social security office to check on his eligibility. She found that temporary beds are available in a respite medical group home. He would need to get
across town and the facility does not have transportation. The hospital calls a cab for Mr. Foster and gives him follow up care instructions, an appointment card for the clinic, and phone numbers for the various disability agencies he needs to contact. He gave permission for his aunt can be called and she has agreed to meet him at the group home and start to work with him to get a stable living situation.

Question 3.8

What factors are most important in Mr. Foster achieving healthy living over the next two years?

<table>
<thead>
<tr>
<th>Answer 3.8 and Related Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connecting Mr. Foster with services and supports may be the most important factor in putting him on a path to a stable, healthy life. The hospital social worker made some important calls to Medicaid, DD services, and to his aunt. However, sending him in a taxi to respite and relying so much on his aunt is questionable. Although she agreed to meet him at the group home, the prospect of starting from scratch and negotiating with all of the services delivery systems is daunting. In addition, Mr. Foster’s difficulty with social interaction related to his ASD may make it even more challenging to be comfortable in the respite medical group home. It would be very helpful if the hospital social worker had either offered to meet with the aunt and help her with the paperwork or made arrangements with someone at the respite center to do so. His aunt will need support and she may not be able to make such a commitment. It may be worthwhile to contact the developmental disability system to request a case coordinator to be assigned.</td>
</tr>
<tr>
<td>Once he recovers from his current illness, it will be important to have a conversation with him about what he wants for his life including where he would like to live, work, and recreate. It will be tempting to make decisions quickly for him based on available beds and programs; but it is important to engage him in making these decisions. The risk is that he will walk away from the service delivery system and return to street life.</td>
</tr>
</tbody>
</table>