

## **Critical Need for Dental Care Among Those With I/DD**

Meet “J” a 41-year old man with Intellectual and Developmental Disabilities, who has a mental age of about 6 months, PICA (chews or eats inappropriate objects), and cannot have a routine tooth cleaning without being fully anesthetized. Without those routine cleanings, J would be at high risk of losing his teeth, would not keep dentures in his mouth, but would greatly increase the staff support needed for him to eat his meals. Worse, he would be at high risk of contracting life-threatening infections of his teeth, brain, or digestive tract.

As an I/DD Waiver recipient now living in a group home, J’s Medicaid covers neither these critically necessary cleanings nor other tooth-preserving dental services. The Commonwealth of Virginia promised J would continue to get his teeth cleaned three times a year after his state-run Intermediate Care Facility was closed, but as a result of the program start up, it took a year to arrange his first cleaning, and there are delays getting his second. Nonetheless, J is fortunate to live where there will be a supplementary dental program for those on Medicaid Waiver.

In general, Medicaid only covers medical emergencies for tooth extraction and follow up remedial care. A few states offer a dental benefit of about \$500 for routine cleanings – nowhere near enough to pay for full anesthesiology. Individuals on Medicaid waivers and their families generally have great difficulty finding dental services on their own. Typically, it is the Case Manager or residential provider who finds whatever services are available.

### **Some other states provide dental benefits to supplement Medicaid, for example:**

- Connecticut makes it easy for people with I/DD to find private dentists who perform routine services on their website and by including a toll-free number on Medicaid cards. It operates dental clinics located at its four remaining Intermediate Care Facilities. Patients requiring anesthesia must go to the UConn Dental School or a state hospital.
- In Massachusetts as a result of a court order in 1976, Tufts University Dental School operates five clinics statewide offering comprehensive dental care to those with I/DD, while training its Dental School graduates to understand how to serve this population.
- Virginia is just now establishing a comprehensive dental program to supplement Medicaid for waiver recipients by contracting with private local dentists.
- Louisiana State University appears to be the only provider of dental services outside of Pinecrest Supports & Services Center, the last ICF for those with I/DD located in Central Louisiana. Anyone needing full anesthesia for routine cleanings must be referred to University Hospital that offers treatment to a given individual only once every 5 years.
- In Kentucky, the Lee Specialty Clinic located in Louisville offers dental services to those who can travel to the clinic. *(See the reverse side to read more about this model clinic and dental program)*

These programs illustrate the types of solutions needed by people with I/DD nationwide. We request that Centers for Medicare & Medicaid Services (CMS) review the direct and indirect costs of inadequate dental care for those with I/DD, including all challenging complications, to determine the net benefit of expanding dental coverage for I/DD Waiver recipients. CMS could use the state and private programs profiled above as case studies for expanding dental service delivery while also constraining costs. In addition to paying directly for individual services, we propose that CMS fund initiatives that support programs designed to increase the number of clinics, training facilities, and ultimately dentists, hygienists, and anesthesiologists offering services to the I/DD population.

## Lee Specialty Clinic Program

*Matt Holder, MD, MBA, and CEO of the Lee Specialty Clinic in Louisville, Kentucky, described the clinic's program and funding arrangement:*

At the clinic, we provide interdisciplinary care: Primary medical, psychiatry, neurology, physical/ occupational/ and speech therapies, behavioral analysis, psychology, nutrition, audiology, podiatry, physical medicine and rehabilitation, endocrinology, gynecology and, of course, dentistry. Our dental program features the only dental residency in the nation where trainees treat 100% people with I/DD throughout the duration of their training. Additionally, all of the dental students and dental residents from the dental school rotate through our clinic so that we can get more dentists out there who are willing to see people with I/DD. We have a grand total of about 1,300 patients at the clinic who come from about 60 counties in Kentucky, some traveling 4 or 5 hours each way to get to us. Unfortunately, we also have a waiting list of about 200-300 people.

When it comes to patients who need anesthesia for routine cleanings, we have a very different approach. First and foremost, we believe that general anesthesia is the most aggressive form of restraint possible and one that deprives the patient of the chance of learning how to function properly in a routine dental visit. So, general anesthesia (GA) is usually a last resort option. The average referral rate to patients with I/DD to the operating room for GA is around 25%. Our cross section of patients is more heavily weighted with moderate, severe and profound ID, along with concomitant psychiatric diagnoses - so one would expect our rates to be even higher than 25%. Ours referral rate is less than 2% - We employ a variety of other methods that help us avoid the overuse of GA for routine dental care.

We offer general dentistry (and all that encompasses), dental hygiene, plus we can do dentures and crowns at low cost. We have a network of prosthodontists, periodontists, endodontists, oral surgeons and oral pathologists who we refer to when a case gets too complex for what we can handle in the clinic.

As for how we pay for it, we advocated for a very, very, very long time for the creation of a new clinic license in Kentucky called an Intermediate Care Clinic license. In Kentucky, this allows us to contract with the state in a cost-based fashion, much like a Federally Qualified Health Center (FQHC), except 100% of our patients have I/DD, so the parameters that we are judged on are designed for people with I/DD rather than trying to fit patients with I/DD into the other box that patients without I/DD find themselves.