

# Oral Healthcare for Persons With Intellectual or Developmental Disabilities: Why Is There a Disparity?

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## *Abstract*

*Despite some progress, a significant disparity still exists in oral healthcare between individuals with intellectual or developmental disabilities and the general population. Barriers generated by finances, a lack of appropriately trained dental providers, and the patients themselves combine to create significant challenges to providing dental care. However, strategies exist that can help to decrease the magnitude of these hurdles so this disparity can be minimized.*

All individuals deserve the opportunity to receive dental care; however, not all individuals can readily access the care they need. Historically, one such group is people with intellectual or developmental disabilities (ID/DD). It is estimated that more than half a billion people worldwide have a physical, intellectual, or developmental disability.<sup>1,2</sup> It has also been reported that over the past few decades an increase in intellectual disabilities has occurred,<sup>3</sup> with a prevalence of 1.5% to 4% having been reported.<sup>3</sup>

In addition to an increase in this population, there has also been a shift in the living arrangements of this community. In the past, many of these individuals resided in institutions, many of which had the ability to provide dental care on site within the institution.<sup>4,5</sup> More recently, however, many of these individuals have been moved from institutions to their family homes or group homes.<sup>6,7</sup> This societal change has resulted in a shift to dental services being provided by practitioners or agencies in the community.<sup>6,7</sup> A recent study examining how patients with developmental disabilities accessed dental care reported about 40% used private practitioners while another 35% relied on community dental services.<sup>8</sup>

When considering the oral health of individuals with ID/DD it is often reported that they have significant dental needs and that these needs are often untreated. In fact, as early as 1979 the National Conference on Dental Care for Handicapped Americans reported that the number one unmet health need for this population was adequate dental care.<sup>9</sup>

These unmet dental needs often result in these individuals having poor oral health, with dental needs that are more severe than for individuals without ID/DD.<sup>8,10</sup> These unmet and significant dental needs often impact the daily activities of these individuals, which has a negative impact on their quality of life.<sup>3,6</sup> These unmet dental needs appear to include all dental parameters. When looking at oral hygiene, for example, studies show that patients with ID/DD have poorer oral hygiene with more gingivitis and periodontal disease.<sup>1,3-6,11-16</sup>

This same disparity is seen when using dental caries as the variable. Individuals with ID/DD also demonstrate more dental caries than the general population.<sup>1,3,5,11,14,16</sup> Often this results in pain<sup>12</sup> and an associated increase in extractions for these individuals.<sup>16</sup> Of course, all of this can be exacerbated by a diet that is often high in carbohydrates.<sup>17</sup>

## Disparity in Oral Health

Although a previous US Surgeon General's report indicated that a significant disparity exists in the oral health of individuals with ID/DD and their typically developing counterparts,<sup>18</sup> it would be important to know the extent of this disparity. A study published in 2011 demonstrated that this disparity begins at a very early age. The authors reported that children with ID/DD were more than 30% more likely to have their first dental visit delayed.<sup>19</sup> In addition, studies have shown that children without ID/DD were more likely to receive preventive care.<sup>20</sup>

This disparity extends beyond just preventive services. It has been reported that even if the ID/DD population receives preventive care, they are less likely to receive necessary restorative care,<sup>7</sup> resulting in a higher level of untreated disease, including both dental caries and periodontal disease.<sup>11</sup> In fact, individuals with ID/DD are reported to demonstrate disparities in many aspects of general health, including smoking, obesity, and the use of various screening modalities such as those for breast and cervical cancer.<sup>21</sup>

With this disparity in oral health being so apparent, it seems that an understanding of why it exists, along with the barriers that help propagate it, is necessary in order to find needed solutions. In general, it is mostly agreed that two historical factors that made these disparities more evident were deinstitutionalization and an increase in the life expectancy of this population.<sup>18,22</sup> As an example, over the past 40 years the life expectancy of an individual with Down syndrome has increased by more than 50 years.<sup>18</sup> Although it is beyond the scope of this article to expand on the medical advances that have resulted in this increase in life expectancy, it seems logical that an aging population requires more health interventions, which can increase this disparity.

The role that deinstitutionalization has played in this health disparity took decades to unfold. Starting in the 1960s there was a move to take individuals with ID/DD out of institutions and move them into the community.<sup>9,18,23</sup> From the perspective of providing oral healthcare, these individuals could no longer receive their dental care through the institution but instead had to rely on community services.<sup>9,18,23</sup> In the case of dentistry this meant that private practitioners, most of whom had little to no experience working with these individuals, had to address the treatment needs.<sup>9</sup> The role of the dental practitioners as a barrier to eliminating this disparity will be discussed later.

## Barriers to Dental Care

As mentioned above, barriers exist that make it challenging for individuals with ID/DD to achieve necessary dental care. These barriers can be grouped into four major categories: patient-centered, provider-centered, financial, and educational.

Patient-centered barriers to care include the patient's anxiety, associated comorbidities, and the degree of the individual's disability ([Table 1](#)). Multiple studies have demonstrated that patient anxiety is one of the strongest barriers to care.<sup>5,7,12</sup> Studies have shown that the anxiety experienced by an individual with ID/DD may impact the desire to avoid dental care more than external factors such as transportation and cost.<sup>7</sup> This avoidance, of course, impacts overall dental health.<sup>11</sup>

A study in 2002 examined, in detail, this fear-related behavior. The authors reported that nearly three quarters of the subjects reported anxiety as the greatest barrier to receiving dental care. In addition, this anxiety-based avoidance was far greater in individuals with ID/DD than it was for patients without a disability. An interesting finding was that caregivers and parents were unable to accurately estimate the fear of these patients.<sup>24</sup>

The study also demonstrated that this level of fear varied between individuals based on their level of disability.<sup>24</sup> Other studies have also demonstrated that the level or degree of disability is negatively correlated to seeking and receiving dental care.<sup>5,15</sup>

One additional patient-centered barrier to consider is the medical comorbidities that are commonly associated with ID/DD.<sup>5,15,22</sup> It is possible that the comorbidity may be more common in the individual with ID/DD. Although these comorbidities can occur involving any organ system, an often-cited example is a seizure disorder. This medical condition itself may impact how dental care is provided but this is compounded by the gingival hyperplasia often associated with the medical therapy.<sup>12,18</sup>

Another barrier to obtaining dental care for individuals with ID/DD is cost.<sup>3,10,12,24</sup> In fact, it is often reported that cost is the single most reported barrier, greater than 40% in some studies.<sup>24</sup> Finances can be such a significant issue that a 2013 editorial noted that having a child with an ID can directly and negatively impact a family's financial stability.<sup>25</sup>

It is often mistakenly believed that individuals with ID/DD are insured through Medicaid and, therefore, should be able to obtain dental care. Unfortunately, Medicaid often provides no dental coverage or coverage for emergency procedures only.<sup>18</sup> Even if dental coverage is provided, in many states it is often terminated when the patient turns 21 years of age.<sup>26</sup>

Even if the individual has dental coverage through Medicaid the majority of dentists do not accept Medicaid, although the percentages vary from state to state. Various reasons have been given but often it is reported that Medicaid reimbursements are low and providing care for someone with an ID/DD often may take more time than for a typical patient.<sup>18,27,28</sup> To many dentists, this can be a significant factor considering that in 2014 the income of dentists was reported to be decreasing.<sup>29</sup> A high rate of failed dental appointments among Medicaid participants is also a concern.<sup>9</sup>

An additional barrier to care may be the dentists themselves.<sup>12</sup> Numerous studies have been conducted to determine why more dentists do not provide care to patients with ID/DD.<sup>1</sup> The majority of these studies cite the most common reasons as the patient's behavior, severity of dental disease, extent of the patient's disability, and a lack of training or experience treating this population ([Table 2](#)).<sup>1,4</sup>

Usually, these patients are treated by pediatric dentists<sup>16</sup>; however, as these patients age there is a need to engage the skills of the general dentist to provide necessary care.<sup>8,10,26</sup> Unfortunately, it is often these general dentists who feel ill-prepared to provide this care because of a lack of training in working with this population.<sup>25,27</sup>

If the desired outcome were to have more general dentists feel comfortable treating patients with ID/DD, it would make sense to examine why private practitioners do not have this comfort level.<sup>10,23,25,28,29</sup> Most studies point to the lack of training in working with this population in the dental school curriculum as a significant factor.<sup>23,28</sup> A lack of educational experiences working with this population results in dental school graduates who have never gained the confidence to work with these patients.<sup>9</sup>

It is interesting that this lack of experience would continue to be a barrier given two major historical educational and societal changes. In 2000 the Surgeon General's report "Oral Health in America" highlighted that individuals with special needs are one of the most underserved populations.<sup>18,30</sup> Five years later, the Commission on Dental Accreditation (CODA) implemented two new standards that all dental schools were required to meet. These two standards made it mandatory for dental graduates (dental and dental hygiene students) to be competent in evaluating and determining the treatment needs of individuals with special needs.<sup>2,13,18,19,27,29</sup>

## Why Barriers Still Exist

If the need for training dental students to this level of competency is both needed and required, why does this barrier still exist? Although CODA made this training mandatory, it did not provide details on how it had to be completed. In 2003 it was reported that from 1993 to 1999 the average number of hours in the dental curriculum devoted to patients with ID/DD actually dropped by more than 50%, with the majority of dental schools reporting less than 10 hours of clinical teaching.<sup>18</sup> Some improvement was reported in 2010 with more than 90% of the schools reporting covering dental care for these patients in their clinical curriculum, although only two-thirds offered a separate course in this area of study.<sup>27</sup> The vast majority of these schools did not have a separate clinic or staff dedicated to treating these patients, and most exposed dental students only to the most frequently occurring disabilities such as Down syndrome and autism spectrum disorder.<sup>27</sup>

Although some progress has occurred, it appears that even though dental students deserve this training<sup>27</sup> it still does not universally occur. A variety of reasons for this have been reported. Previous studies have indicated the major reasons for this void in training include a lack of patients, faculty expertise, clinical sites, educational resources, and time in an already overloaded curriculum.<sup>27,30</sup>

A 2009 survey sent to the Deans of all of the medical and dental schools in the United States seemed to echo these reasons. Only 47% of the dental school Deans felt that their graduates were competent to treat patients with ID/DD, while 50% reported that adding this experience to the curriculum was not a high priority at their own schools.<sup>2</sup>

## Removing the Barriers

Clearly there are many barriers in the way of providing dental care to individuals with ID/DD. The question is whether or not these barriers can be eliminated or at least made slightly less formidable. Some possible changes have already been noted here. Providing better reimbursement for dental services rendered for these patients along with full and complete implementation of the CODA standards are some others. In addition, changing providers' attitudes regarding working with this population would help to overcome the barriers related to dental providers.<sup>1</sup>

Dental providers could also help increase access for these patients by offering adjunctive services that make it easier for them to accept dental treatment. For example, if behavior management was a barrier, a dentist who provides a range of options would be helpful. Studies show, for example, that parents of children with ID/DD are accepting of the use of protective immobilization or stabilization in order to accomplish dental care.<sup>31</sup>

Two additional services used to manage behavior that can be useful are sedation and general anesthesia. Although both of these are associated with certain risk and can have some unpredictable results with this population,<sup>32</sup> they both can play a role in getting dental treatment completed.<sup>7,8,32,33</sup> Of course, when using any pharmacologic adjunct it is important to choose what is best for the patient and not what is more convenient for the practitioner.<sup>8,33</sup>

Another possible approach to a solution would include education of more than just dental professionals. Many experts recommend that education should include the entire team responsible for the patient.<sup>4</sup> This includes the patient's parents or guardians' along with other health professionals such as speech and language therapists, occupational therapists, and psychologists.<sup>12,17</sup>

Inventive approaches to modifying a patient's home care are another way to eliminate some of these barriers.<sup>10</sup> Studies have shown that introducing oral hygiene instruction in a stepwise fashion results in increased compliance.<sup>10</sup> Binkley et al in 2014 reported a statistically significant improvement in both oral hygiene status and oral hygiene practices themselves after the implementation of a four-step oral health strategy.<sup>14</sup>

## Serving as an Advocate

Although there are numerous strategies to try and overcome these barriers to care, perhaps the best approach is to focus on changes on the organizational level. An example of this is Special Olympics. As an organization, Special Olympics provides much more than athletic opportunities; it serves as an advocate for individuals with ID/DD, providing over a half dozen Healthy Athletes disciplines, including Special Smiles. These disciplines provide not just screening examinations but also direct treatment interventions or the appropriate referrals.<sup>3</sup> It can be easily argued that perhaps the most important service Special Olympics provides is educating the public about working with people with ID/DD.

There are many barriers that make it difficult for individuals with ID/DD to receive dental care, but it is important that the dental community finds ways to overcome them. Reports from organizations ranging from the Surgeon General of the United States to the American Academy of Developmental

Medicine and Dentistry to CODA to Special Olympics all agree, this disparity in oral health must be addressed.<sup>2,3,18,30</sup> Every oral health provider can play a role in achieving this goal.

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**TABLE 1****Patient-Centered Barriers to Care**

<b>Patient-Centered Barriers</b>
- Patient's anxiety
- Associated comorbidities
- Degree of disability

**TABLE 2****Provider-Centered Barriers to Care**

<b>Provider-Centered Barriers</b>
- Patient's behavior
- Severity of dental disease
- Extent of patient's disability
- Lack of training or experience treating this population

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