Unlocking the World of Travel for Individuals With Intellectual and Developmental Disabilities

Alice Hamilton 1, Rafik Jacob 2

1. Internal Medicine, University of Florida College of Medicine – Jacksonville, Jacksonville, USA 2. Internal Medicine, University of Florida College of Medicine – Jacksonville, Jacksonville, USA

Corresponding author: Rafik Jacob, rafik.jacob@jax.ufl.edu

Abstract

The article explores the challenges faced by families with Intellectual and Developmental Disabilities (IDD) individuals when it comes to travel, drawing parallels with the difficulties experienced in attending routine doctor’s appointments. The disruptions to routine, preparation of supplies, and the fear of unfamiliar environments often make travel seem like an unattainable dream for these families. Despite these challenges, some families showcase resilience and determination, managing to travel with their loved ones. The article emphasizes the inconsistency in experiences across families due to varying levels of cognition, adaptive functioning, financial means, and available support. It discusses the additional complications for families dealing with medical procedures, the scrutiny of strangers, and financial difficulties. The article suggests the crucial role of primary care physicians in facilitating travel for these families by performing pre-travel medical assessments, consulting social workers, and preparing comprehensive emergency plans. It proposes the need for collaboration between governments, the tourism industry, advocacy groups, and the community to address these challenges. Ultimately, the article advocates for the empowerment of families with IDD individuals to enjoy the world as tourists, with the support of their primary care providers.

Categories: Family/General Practice, Internal Medicine, Health Policy
Keywords: behavioral issues, financial difficulties, pre-travel medical assessment, primary care physicians, challenges, travel, intellectual and developmental disabilities

Editorial

Travel has the power to transform lives, but for families of individuals with Intellectual and Developmental Disabilities (IDD), it often seems like an unattainable dream. In this article, we explore the challenges faced by these families and how to overcome them.

Put yourself in the shoes of a family with an adult child with intellectual and development disabilities, trying to arrive at a doctor’s appointment in a timely manner. To start, this is often a departure from a carefully and lovingly crafted routine that works well for the family. Then, there are hours of preparation for the supplies, movement of mobility equipment, loading into the car, unexpected stops on the ride, and finally, what feels like endless waiting in different rooms of an office that is often unable to accommodate them in any meaningful way. How would this affect your interest in booking additional appointments?

Now, do all the above again—but pay to do it in a foreign environment surrounded by strangers.

The fear of the unknown and what may go wrong can be enough to stymie anyone’s interest in travel, but there are some families that have made incredible personal efforts to travel with their loved ones who have IDD, showcasing their resilience and determination. This is especially important in this population when the individual may not always be able to articulate their own desires. While every individual may not be able to express themselves, it is at this time we must consider the words of those who came before them who also lived with IDD and were able to share their experiences. In a qualitative study based on interviews of such patients, they describe how meaningful these experiences were [1]. The interviewed subjects all unanimously enjoyed their time as “normal” tourists and wished to travel more in the future. If they were able to enjoy, remember, and long for the experience of travel, what stops others from doing the same?

The only thing that is consistent about experiences across families of individuals with IDD is that it is highly inconsistent as they vary significantly from one another’s in terms of cognition, adaptive functioning, financial means, available support, and what unique challenges they face on a particular excursion.

For some families, medical procedures such as catheterization, suctioning secretions, and providing nutrition via a gastronomy tube have become commonplace. However, every step of these procedures is complicated by leaving the home environment—packing excesses of the appropriate supplies, complying with airline policies, finding an appropriate and sanitary location, and potentially needing to change plans at a moment’s notice.
For others, it may be the fear or feeling of scrutiny by strangers about their individual’s behaviors. These behaviors may not directly affect the people they are around, but the limited and valuable expression of different needs or emotions by vocalizations and movements can sometimes attract uncomfortable attention. All parents dread a child's tantrum on a trip outside the house, but for these families, an outburst could result in extreme agitation, aggression, self-harm, or days without sleep.

Financial difficulties are a significant barrier, compounded by diminishing government support. This is particularly true for many of the families who end up making the decision for one parent to stay home as a full-time caregiver and cede their dual income household for the sake of their child’s welfare. It is difficult to quantify the financial impact of having a child with IDD across different etiologies, but there have been several studies on conditions like Down syndrome which describe the permanent losses in earning potential and household savings [2]. Across the board, this limits all expenditures on leisurely activities and particularly travel outside of their local area. Additionally, limited awareness and inconsistent inclusivity standards within the tourism industry also deter travel as places lack the ability to accommodate these families.

In the end, there is no quick solution for facilitating travel for families with individuals IDD. However, the same way that the experience of travel holds so many parallels to attending a doctor's appointment, the primary care physician can play a crucial role in empowering families to make informed travel decisions. From the moment that the individual with IDD and their family expresses interest in travel, the physician can begin performing a pre-travel medical assessment to consider what obstacles the family might face upon traveling beyond their regular boundaries. This assessment can include considering the portability of the patient’s medications, mobility device durability, accessibility of larger quantities of medical supplies, and even helping to create a comprehensive emergency plan for the family if plans go awry.

This is also an appropriate time to, if possible, consult social work to help with these preparations and to consider creating a document summarizing the patient’s medical condition to help in the event of requiring medical care in their travel location of choice. There may even be a need for an entire appointment in preparation for a vacation to ensure stability of all pre-existing conditions and to also address preventative measures that may be indicated. For example, patients with severe motor and intellectual disabilities (SMID) are at an increased risk of deep venous thrombosis at baseline [3]. Therefore, longer travel times further increases their risk of a vascular concern and should be taken into account prior to any travel. Similarly, individuals that are nonverbal may be unable to communicate more complicated feeling such as dehydration or motion sickness. To counter this, maintaining a log of the individual’s fluid intake at home prior to vacation can ensure that families are able to continue the same or increased level of hydration while away from the home.

It is important to recognize that, even after preparing thoroughly for the trip and taking action to prevent the above complications, there are times where the individual is unable to enjoy the vacation. In anticipation of this dreaded but always possible outcome, it is essential that the families have purchased trip insurance. This allows them to recover a portion of their initial spending and reduce the risk of developing resentment against the individual for factors that are often outside of their control.

By offering any number of the supportive measures listed above, the physician and other members of the medical team can facilitate an extraordinary experience for these patients and their families. Even a trip short in duration and distance from the home can be life-changing and relieve caregiver burnout. It is also crucial to acknowledge the fact that this problem stretches far beyond the individual and their primary care provider. Addressing these challenges requires collaboration between governments, the tourism industry, advocacy groups, and the community.

Conclusions
There is no denying that families of individuals with IDD can face many difficulties to reach a doctor’s appointment and the dream of traveling to a destination for leisure can feel elusive. However, there is no reason that these families should be restricted from enjoying the world as tourists and they might just need the support of the primary care provider.

Additional Information
Disclosures
Conflicts of interest: In compliance with the ICMJE uniform disclosure form, all authors declare the following: Payment/services info: All authors declare that no financial support was received from any organization for the submitted work. Financial relationships: All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. Other relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

References
