Accessible transportation consultation

Submission of Robin Bayley, as an individual

I am writing to participate in the Accessible transportation consultation of the Canadian Transportation Agency, under The Regulatory Modernization Initiative.

I write as a person with multiple and severe food and environmental allergies who has experienced barriers within the air transportation system almost every time I fly. Current accessible air travel regulations and codes don't address the barriers I face, nor does the system of regulation readily lend itself to including me or people like me. But that's not a valid reason not to try. We need a regulatory system that is broad and inclusive in disability coverage, which applies uniformly to carriers and which provides certainty regarding process but is not overly prescriptive in outcome. It's a tall order and it requires a good deal of change.

The Agency asks two questions, which I undertake to answer, providing examples of barriers from my travel experience, which I feel supports the need for broad and inclusive, uniform Regulations. Those questions are:

1. Could we achieve a more accessible transportation network by converting existing voluntary codes of practice into regulations?
2. Should accessibility-related standards – such as the one-person-one-fare rule and requirements to accommodate persons with severe allergies etc. – already established for some transportation service providers through Agency decisions, be applied more widely to create a level playing field and to ensure that persons with disabilities have a consistent level of accessibility throughout the network?

My answers and recommendations are that, yes, there should be uniform regulations with broad application, but there are still substantial gaps and significant barriers that must be addressed regarding accommodation of allergic disability that must not be allowed to remain in any new regulations.

My answers stem from the following beliefs:

1. **The regulatory regime should cover persons with all types of disabilities, including passengers with allergies.**
2. **Allergic passengers should enjoy the same choice of air carriers and routes as other passengers**. Thus, accommodation should include best practices and apply equally to all carriers operating in Canada. Allergic passengers should not have to limit their travel plans by the destinations of the airline that best addresses their individual allergy risks.
3. **Allergic passengers should enjoy the same carry-on luggage allowance as other passengers**. Thus, they should have the supplies they must carry due to their

allergic disability recognized as medically necessary items subject to an exemption from carry-on limits.

4. **Allergic passengers should be allowed to access the same array of seats, including premium seating, as other passengers**. Thus, they should be able to book seats anywhere on the plane without undue efforts, and have their condition accommodated in those seats. They should not be re-seated against their will and without consultation or denied premium seating because one-size-fits-all medical codes cannot differentiate between able-bodied and reduced mobility passengers.
5. **Allergic passengers should enjoy full protection of the buffer zone**. Thus, carriers should ensure that anyone sitting in the buffer zone understands the briefing and the restrictions imposed, and personnel should monitor and enforce zone restrictions. The briefing should be standardized so that it is timely, prescriptive, specific, understood and enforced. The "self-help" cleaning rule should be abandoned or made more of a partnership.
6. **Severely Allergic passengers should enjoy protection from risk of exposure to their allergens, regardless of those allergens and where they occur in the transportation system**. There is no logic behind restricting the requirement to accommodate to nuts and certain types of pets, and the only reason for this limitation is that only successful complaints relating to those allergens have made it to the decision stage.

Several allergy-related accessible transportation cases were cited in the discussion paper. I provide a brief critique that is not meant to be exhaustive, but which should be sufficient to point out that if regulations are drafted, they should be subject to a much broader consultation process than was used when the decisions were rendered. This would allow the latest science to be considered and the experiences of a greater number of people who experience barriers due to their allergic disability. Those decisions only considered issues brought forward in complaints and do not consider all barriers throughout the system or even all those for which air carriers are responsible.

The Discussion Paper cites Decision No. 134-AT-A-2013, which has several major deficiencies, in my experience and opinion. It mentions, "precautions that persons with severe allergies would be expected to take in their daily lives" as if that is a well established phrase with specific measures outlined somewhere. It seems to have been used casually by one of the experts consulted, but I have never been able to find out what those precautions might be (other than avoidance, which does not apply here), or how "everyday life" precautions might be undertaken in an airplane interior, where an individual has no control. I have seen no evidence that those unnamed measures were explored or queried.

The discussion paper cites a Minister of Transport inquiry in which an Inquiry Officer recommended that a person with allergies put themselves in intentional contact with allergens and clean their own space ("abatement, by allowing passengers to wipe down their seating areas"). This is like asking a person without use of their legs to enplane

early to drag themselves to their seats, a grotesque thought that flies in the face of all principles of disability accommodation, such as honoring human dignity. How we are to clean allergens from porous surfaces such as seatbelts and upholstery has never been explored. How would we protect ourselves from the allergens therein? Maybe doing it with double-gloves like surgeons, but then how would be dispose of contaminated materials? Would they average individual have the expertise to do this safely?

The decision is cited as containing the following requirement, “an announcement to other passengers within the buffer zone that they **must refrain** from eating peanuts, nuts or sesame seeds or foods containing these”(emphasis added), but in my experience, announcements fall far short of a prohibition. They are often more in the nature of a polite request. If there were an allergy accommodation Regulation, the wording could be standardized and given the weight of other safety briefings such as the exit row seat. I have never witnessed the staff member delivering the briefing ensure that the message was understood and that the people sitting in the zone were willing, as I have for the exit row briefing. Further, I have never experienced monitoring or enforcement of a buffer zone, much less within a voluntary briefing zone on an airline not subject to a food allergy decision. I have experienced such briefings taking place well after take-off and by which time individuals in the buffer zone have consumed food they brought on board. I have been personally identified in such an announcement, against my will, due to the risk of backlash. A regulation could standardize and raise the standard of buffer zone briefings.

In Inquiry Officer recommends “training flight crews on signs and symptoms of an allergic reaction.” Does it stop there? How about requiring carrying Epipens (with current expiry dates) in first aid kits and training staff how to use them? Studies of Epipen administration in schools have indicated that 20-25 percent of administrations are for people who have no prior knowledge of having an allergy, so requiring allergic individuals to bring their own doesn’t go far enough. And if a safe landing spot is not readily available, an individual could run out of Epipens before reaching assistance.

There is little evidence in the decision that the expert’s comment that other allergens could not be accommodated was questioned. It is highly unusual for a comment beyond the scope of the complaint to be incorporated, especially when not fully examined. For instance, sesame is included in airline menus in forms that are very easily transferred to surfaces (e.g, in hummus as a dip that gets on fingers), and a recent study found that surface transfer is a greater risk than airborne.

I also see little evidence that reseating as a solution was fully explored for its practical implications. If an allergic individual was seated early in order to clean the area, are they expected to do it again and would they likely have supplies for that? What if there were turbulence and they were required to fasten their seatbelt and stay put? What if there were other allergens such as pets in other potential seats? What if food allergens had and were being consumed in the proposed new seating area because those passengers

were not given the allergy briefing. No, reseating the passenger introducing the allergen is the more workable and fair solution.

The discussion paper talks about differences in risk posed by different types of travel, making an unsubstantiated assertion that "passengers travelling on buses would generally be able to obtain relatively quick access to medical care in the case of a serious allergic reaction." Having recently driven 5, 500 km across Canada to avoid air travel, I can tell you that in this vast country, emergency health services are not readily available during the relatively short period in which anaphylaxis happens. Epipens have an effective time of minutes and there can be hours between emergency medical services on Canada's highways.

The discussion paper also cites environmental allergy decisions, which also require more thorough analysis before a Regulation can address that issue. "The Agency has also addressed allergies to cat dander in response to complaints against Air Canada and WestJet (Decision No. 227-AT-A-2012 https://www.otc-cta.gc.ca/eng/ruling/227-at-a-2012). In that decision, the Agency found that the accommodation for persons disabled by allergies to cat dander could be either a buffer zone or a ban on cats on a passenger's flight when the aircraft does not have high efficiency particulate air filters or provide 100% fresh air." Is the Agency aware that at least one airline is absolutely inflexible about the location of a cat allergy buffer zone and will not make a similar accommodation for a dog allergy? Passengers are forced to sit at the back of the plane if they want to enjoy a cat buffer zone, in seats that are clearly inferior, based on ratings from sites such as Seat Guru and the airline's own seat pricing policy. Such passengers may be forcibly seated away from family who may need to sit in the bulkhead seat if they travel with an infant or exit row seat for legroom if they are tall. This inflexibility is humiliating, reminding me of outmoded "back of the bus" discrimination.

The Inquiry Officer makes a recommendation that food-allergic passengers bring their own food. Yet, that very recommendation gives rise to another barrier I have faced. None of the Canadian airlines will provide guaranteed allergen-free nutrition. I understand and accept that. Individuals such as myself must, by virtue of his or her allergies, carry all nutrition required for the duration of a flight, including transfers and delays. This need to carry safe nutrition is a bona fide medical requirement.

While airlines freely admit that they cannot (or will not) meet the nutritional needs of severely allergic passengers, at the same time, they do not generally recognize a cooler of food as a medically necessary item, deserving an exemption from the carry-on baggage restriction.

Equivalent examples that are exempted include a cooler of breast milk or diabetic supplies. I have, with huge effort and medical documentation (renewed every year at my expense so it will be current), had airlines agree to this exemption for longer trips, but I go back to square one and have to fight for this right for every trip, and it is made very clear to me that it is a discretionary exception because no CTA Order has ever

required this. In my view, all they need to do is interpret their own policies favourably, but it takes months and inordinate effort to get them to agree.

Summary

In summary, regulations would provide better mobility rights by applying uniformly to carriers. They would be more transparent than airline internal policies, which are not shared in full form, therefore limiting accountability. There currently exists the opportunity to make rules for allergy accommodation broader, addressing more circumstances and aspects of air travel than the allergy decisions addressed. Regulations can be more flexible than decisions because they can be updated with new science. If their drafting process involves an inclusive process, they could significantly enhance the mobility rights of allergic individuals. However, they must not merely reflect the limited and questionable rules arising from the allergy decisions or they will further entrench the discrimination faced by allergic individuals.

Sincerely,

Robin Bayley