**Organization of American States (OAS) Permanent Council Meeting:**

**Commemoration of World Down Syndrome Day**

Statement of Alison Barkoff, Acting Administrator and Assistant Secretary for Aging, Administration for Community Living, U.S. Department of Health and Human Services

* Thank you for the opportunity to be here to commemorate World Down Syndrome Day and discuss the importance of the self-determination, autonomy and full participation of people with Down syndrome and other disabilities in every aspect of life. I look forward to sharing about the United States’ efforts and learning about those of other member states.
* The mission of Administration for Community Living (ACL) is to support the full inclusion and participation of people with disabilities in all aspects of community life, regardless of age, type of disability or level of support need. We do that through policy advocacy across the U.S. government, funding disability and aging networks that provide a range of community-based services and legal advocacy, and funding disability research to inform policy and practice.
* An important aspect of the role ACL and the US government play, both regionally and globally, is to share insights about our laws, promising practices, and lessons learned. So, I’m especially pleased to be with you today.
* The theme for this year’s commemoration -- “with us, not for us” – is at the heart of the work that ACL does. ACL includes people with lived experience, including people with intellectual and developmental disabilities (I/DD) like Down syndrome, in all ACL initiatives. For example, people with I/DD advise the President of the United States on disability policy through a committee that ACL administers and are board members for the disability networks ACL funds.
* ACL’s mission is very meaningful to me personally and has shaped my life and career. Over 40 years ago, when my brother Evan was born with Down syndrome, my family, like others at that time, was told that the only place for him was in an institution. My parents said no. Today, my brother is living in the community, has a great job, an active social life, and is an incredible disability advocate. His story demonstrates how much progress has been made in the United States to ensure that people with I/DD have opportunities be valued, full participants in their communities.
* Unfortunately, this kind of life is too often the exception. For too long, people with I/DD have lacked meaningful opportunities to make choices in their lives. ACL is taking steps to change this by investing in initiatives to help people with I/DD have more autonomy, choice, and self-determination.
* ACL supports self-advocacy organizations that help people with I/DD to gain the skills to advocate for themselves so that they can live the lives they want.
* We are working to change the presumption that people with I/DD lack the capacity to make their own decisions. ACL is collaborating with advocates across the country to develop and educate about alternatives to guardianship, including supported decision-making.
* ACL focuses on expanding the services that many people with I/DD need to live and participate in the community. We also are working to strengthen the direct care workforce that provides those services and to support families who often provide unpaid support. Strengthening the caregiving infrastructure is also a priority for the Biden-Harris Administration.
* Employment is critical for full community inclusion. ACL is focused on expanding opportunities for Competitive Integrated Employment – jobs in typical workplaces where people with disabilities work alongside non-disabled co-workers at equal wages.
* Housing is another key area in which greater independence can make a difference. Most people with I/DD live with their families. Community living opportunities are often limited to group homes; few people live in their own apartments or homes. ACL is leading a partnership among federal agencies to develop innovative, inclusive housing models for people with I/DD.
* Finally. an enduring challenge for people with I/DD is overcoming a long history of discrimination. COVID-19 shone a bright light on this discrimination, with people with I/DD excluded from life-saving treatment and facing barriers in accessing vaccines, therapeutics, and more. The Department of Health and Human Services has prioritized enforcement of disability rights protections and is in the process of updating civil rights regulations that protect people with disabilities against discrimination.
* It is with great pride that I am able to speak to you about the progress the United States has made in supporting Americans with Down syndrome and other disabilities to live independently and participate fully in their communities. But we still have lots of work to do and a long way to go.
* We look forward to collaborating with, and learning from, each of you as we work towards the shared goals of self-determination, autonomy and the full integration of persons with disabilities in every aspect of life.