Background, Aim & Method

**Background:** Individuals living with a neurodevelopmental disability or their caregiver may seek nutrition information to improve their health. This information may pertain to problems related to their disability and/or maintaining wellness. Organizations that support those with disabilities may direct families and caregivers to nutrition information that is credible and applicable to their situation. Awareness of how to locate such nutrition resources may be helpful to individuals, their caregivers, and their clinicians.

**Project Aim:** To describe the quantity and quality of resources that promote good nutrition to those with neurodevelopmental disabilities.

**Method:** A survey of non-profit, government-funded organizations that provide support services to those with neurodevelopmental disabilities was conducted between December 2020 and January 2021. A survey link was sent via email to staff at 59 organizations listed in the Associated University Centers for Developmental Disabilities (AUCD) directory and at fifty state agencies serving those with developmental disabilities. The survey consisted of ten questions and required fewer than five minutes to complete. The survey included questions on availability, types, topics, and quality of nutrition information available as well as any associated costs.

**Results:** Of the 50 state agencies who were sent an invitation to participate, 13 completed the survey. Of the 59 AUCD staff who were invited to participate, 16 responded. The overall response rate was 26.5% for state agencies and 27% for AUCD organizations. Twenty-nine of the surveys were completed however, 2 surveys lacked responses to questions 2 through 8. The combined results were analyzed by frequency of each response.

**Conclusions & Discussion**

**Conclusions**
- About two-thirds of the agencies surveyed provide resources that support good nutrition to those with autism, Down’s syndrome, and cerebral palsy.
- The available resources address both prevention of nutrition disorders (i.e., obesity) and clinical approaches to resolving common problems related to disabilities (i.e., tube feedings).
- The materials are evidence-based. References include research studies and the resources of academic and other government organizations.
- The format of the material is varied. Most are provided digitally or as handouts in clinical settings.
- Most of these services are free of charge.
- More than a quarter of the agencies do not feel that they are matching the interests and needs of the populations they serve.

**Discussion**
Evidence-based resources that match the interests and needs of those with neurodevelopmental disabilities are available throughout the United States. These resources are often provided free of charge and are delivered in a variety of formats. Each organization offers a unique array of services and are open to requests for these resources.

Gaps in the availability, accessibility, or breadth of nutrition information may be present. Of the 27 staff members who responded to the survey, 42% reported that either they were unsure that their services match the needs and interests of the populations they serve, or that their services did not match the need. Further exploration is recommended and may be conducted through a follow-up qualitative survey of the participants who responded that they are willing to provide more information.