



Indiana Autism Needs Assessment: Discerning Regional and Stakeholder Needs



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Abstract

Autism spectrum disorder (ASD) is the most prevalent developmental disorder and may often be detected in the early stages of childhood or infancy. However, many individuals do not receive a diagnosis until later in life. ASD commonly manifests through a combination of communication, socialization and behavioral deficits, such as an inability to express basic needs, understand others' emotions, and accommodate changes in routine. The current prevalence of this disorder in the United States is 1 in 68, which has risen drastically from 1 in 150 at the millennium. The rapid increase results in additional strain on existing autism services, both in the state of Indiana and throughout the United States. Consequentially, added burdens are placed on the families and caretakers of those individuals with ASD. This study seeks to understand the needs for autism services within the state of Indiana, and how those needs differ between stakeholder groups and across regions. The HANDS in Autism[®] Interdisciplinary Training and Resource Center carried out a Needs Assessment Survey from 2014-2015 targeting the aforementioned groups and their perceived needs, challenges, and strengths with regards to ASD. The survey showed two of the greatest challenges as a lack of service providers particularly in rural areas and inadequate funding to finance those services both in urban and rural environments. In order to improve the livelihood of individuals with ASD and their caregivers, results of this survey will help to inform the Comprehensive State Plan, activities of the Indiana Interagency Autism Coordinating Council (IIACC), and funding and policy decisions at the state level.

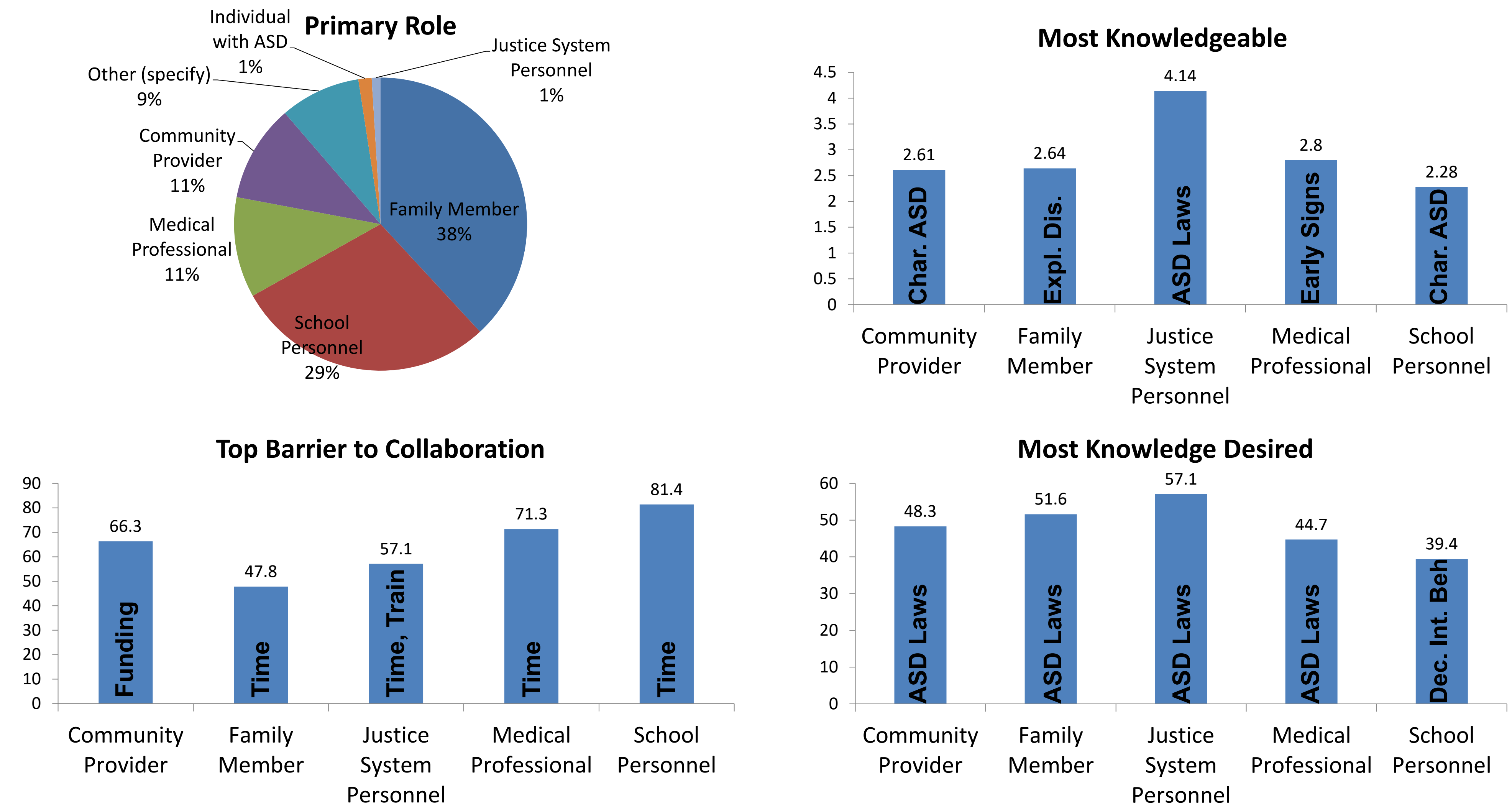
Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that causes deficits in social interactions and is first present in early childhood.^{1,2} The current prevalence of ASD in the United States is 1 in 68, which has doubled from 1 in 150 in 2000.^{3,4} Despite extensive research, there has not been a single gene implicated as the cause of ASD. Current literature asserts the etiology of ASD as a complex interaction between multiple genes and the environment. There are currently no treatments that cure ASD, but steps can be taken to alleviate the main symptoms of the disorder and increase the quality of life for those individuals.⁵ One of the greatest determining factors for success in later life is early intervention. Individuals who receive intensive and developmentally appropriate early intervention show increased social behavior in response to social stimuli. However, accessing the proper services is difficult due to a lack of providers and problems with financial coverage.⁶ Additionally, many of the services available do not use scientifically backed principles or evidence based practices. Therefore, the services being used may not be effective.⁷

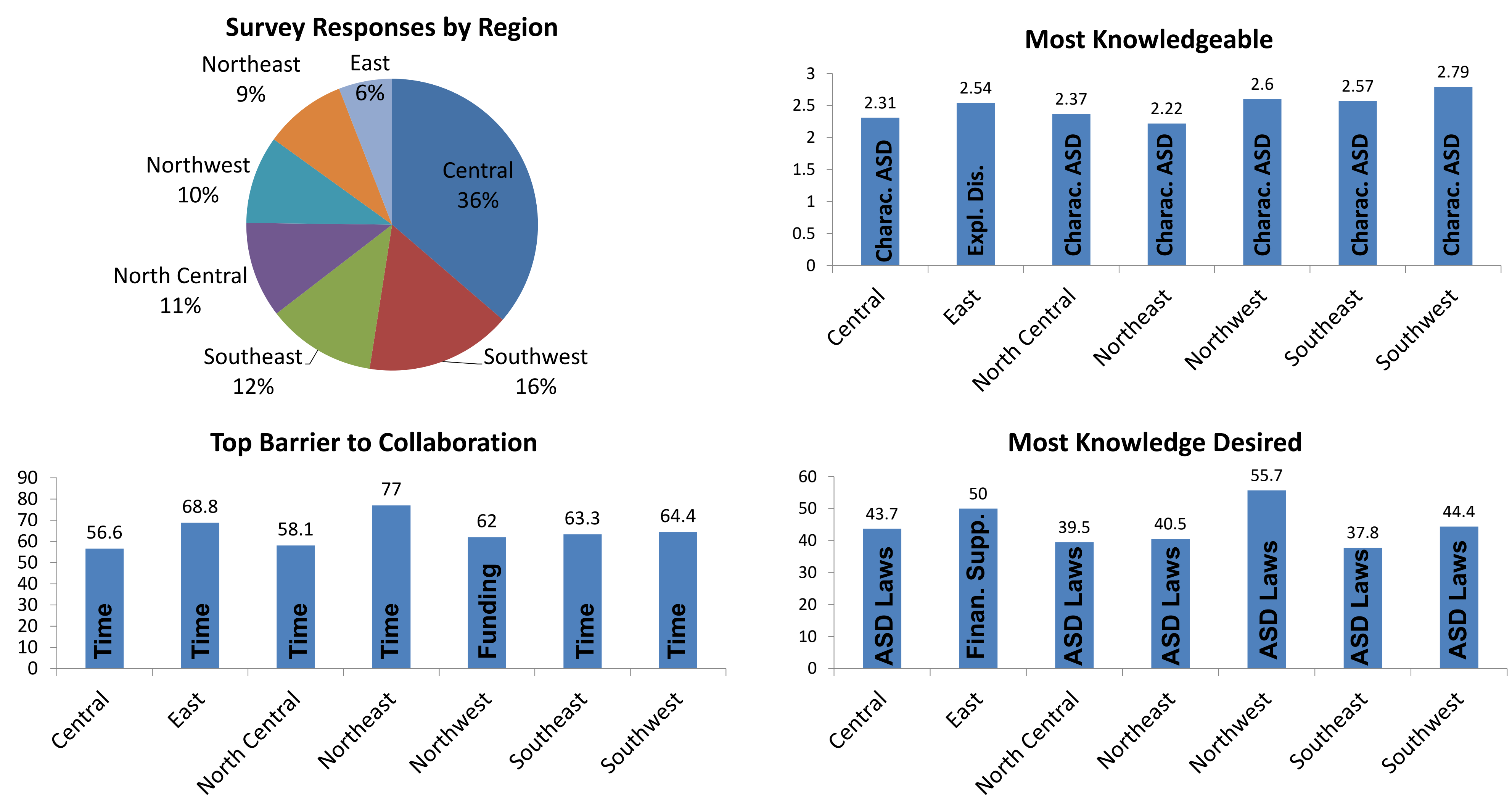
Conclusions

With the data obtained, it appears that the needs for autism services are consistent across the state and between stakeholder groups. Generally, there is little collaboration between groups despite the desire for this. While many of the groups felt their needs were unique, results of the survey indicate that there are greater similarities than initially recognized. The results of this survey will be used to direct a comprehensive state plan and policy development at the state and local levels. Future studies should aim to have more diverse survey responses in terms of ethnic background of individuals surveyed, as well as attempting to reach individuals who do not have access to the internet.

Results by Stakeholder Group



Results by Indiana Region



Methods

Surveys were generated using Survey Gizmo, an online survey instrument, and distributed through email, hard copy, and the HANDS in Autism[®] website. Data was collected using REDCap. Results of the survey were analyzed using Microsoft Excel and IBM SPSS.

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