Abstract

Overview
Down Syndrome (DS) is one of the most common causes of intellectual disability. (Truitt et al., 2011) While there are various resources, support groups and healthcare professionals that are devoted to providing families that have a child with DS with education, support and guidance, few investigators have attempted to assess the utilization of these resources by families or to identify what additional resources are perceived as a need by parents or other experts that work with children with DS. The main aims of this study were to gather further information about: (1) life with a child with DS; (2) resources and supports that are currently being utilized by parents of children with DS, and (3) additional supports that are perceived as potentially beneficial to these families. Comparisons were also done to see if changes in diagnoses, medical care or desires for adult life have changed over time. The information gathered from the survey will subsequently be used to direct and inform the creation of a new educational documentary about DS.

Methods
To complete this study, electronic and paper versions of a self-report survey were distributed to parents, health care providers and educators who work with children having DS. Subject recruitment was completed through collaboration with the members of the Down Syndrome Association of Greater Richmond (DSAGR). Other parents, health care providers and educators in the greater Richmond Area that were not affiliated with the DSAGR, but who are involved in serving people with DS were included in the study as well. A total of 40 surveys were completed online, and 2 were completed in paper version, which were subsequently transferred into the online version. Data was quantified using Microsoft Excel and analyzed using JMP 11 software. P values for particular questions and comparisons of interest were calculated through JMP 11 software.

Results
A total of 42 responses were tallied and analyzed. A majority of the respondents were mothers and the most common age of the child with DS was 5 to 17 years old. Significant data was not able to be obtained in any of the comparisons completed using the data analysis software, so true changes in medical care, diagnosis and feelings of supports over time were not able to be made. About half of the parents assessed by this survey did not feel adequately supported after receiving a diagnosis of DS in their child. Identified areas of additional need for support include within the school system, adult life of individuals with DS, and parental advocacy groups.

Conclusion
A high proportion of parents reported not feeling adequately supported after receiving a diagnosis of DS in their child, which points to the fact that there is still much work that needs to be done to completely support parents and families of children with DS. Specified additional areas of need are within the schooling system, parental advocacy groups and within the adult life structure of individuals with DS. Additional studies need to be done to assess personal emotional supports for parents after receiving a diagnosis. More needs to be done to lower the number of negative experiences that parents have while receiving a diagnosis of DS in their newborn.