



The Impact of Social Distancing on Children with Down Syndrome



Jenesis Yanez MD, Angela Maxwell-Horn MD, Krissy Kalemari DPT, Mattie Goosetree BA
 Vanderbilt University Medical Center, Department of Developmental-Behavioral Pediatrics

Introduction

- In early 2020 COVID-19 began to sweep across the United States.
- People were urged to “social distance”, staying at least 6 feet apart from other people to help stop transmission of COVID-19.
- People with Down syndrome are generally considered to be very social.
- Their social skills are often a strength of their cognitive profile.
- The pandemic placed a near halt on socializing.

Objectives

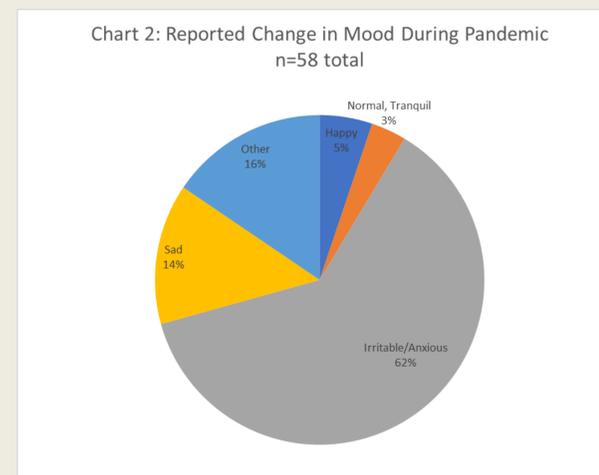
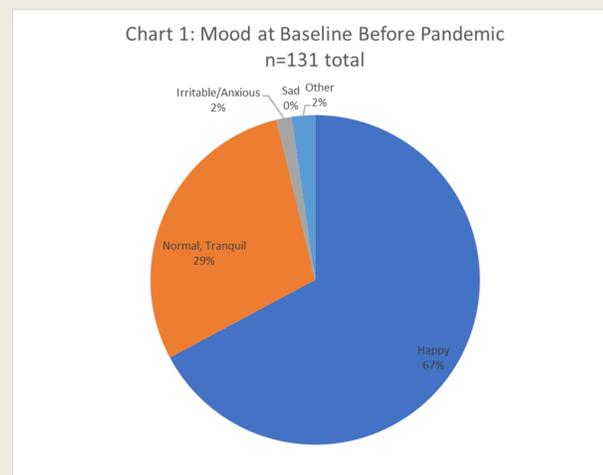
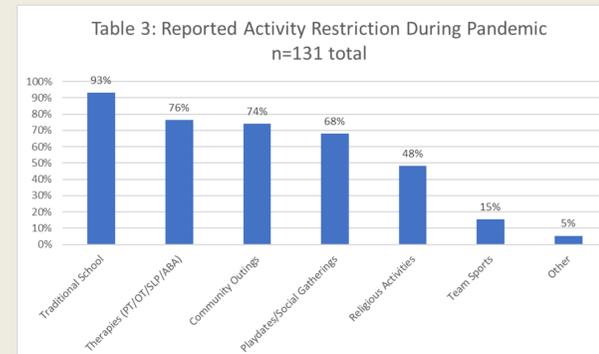
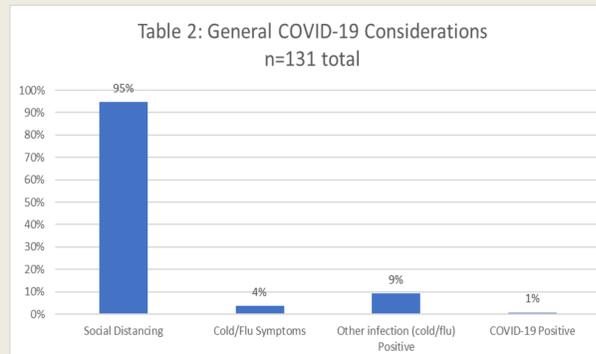
- This study sought to understand how social distancing affects the lives of children with Down syndrome.

Methods

- This survey-based study was approved by the Vanderbilt University Medical Center (VUMC) Institutional Review Board.
- All data were collected via Research Electronic Data Capture (REDCap) between April and June of 2020.
- The survey consisted of 13 questions asked to the caregivers of children with Down syndrome. The questions inquired about mood, eating and sleeping habits, and activities during the period of social distancing due to the COVID-19 pandemic.
- Family members of children who had attended the Down Syndrome Clinic at VUMC between March 2019 and March 2020 were invited to participate.
- A total of 255 families were contacted and invited to participate. 131 of these families participated in the survey study.
- The Down Syndrome Clinic at VUMC serves children from birth through age 18.
- The age of children of participating families ranged from age 1 year of age to 18 years of age.

Results

Table 1: Survey Questions	
1.	Did your child socially distance during the COVID-19 pandemic?
2.	Did your child have any symptoms such as high fevers, cough, or shortness of breath?
3.	Was your child diagnosed with COVID-19?
4.	Was he/she diagnosed with anything else such as a cold or the flu?
5.	In general, what is your child's overall mood at baseline (before social distancing or the pandemic)?
6.	Has your child had any changes in their mood since starting social distancing/the pandemic began?
7.	How would you describe your child's mood since starting social distancing / the pandemic started?
8.	Has your child had any changes in their sleeping habits?
9.	Has your child had any changes in their eating habits?
10.	What activities has your child been restricted from?
11.	What kinds of things has your family been doing since most routine activities were suspended or cancelled?
12.	From where did you get your most helpful information about COVID-19?
13.	Are you willing to be contacted about future studies related to individuals with Down Syndrome?



Results

- Most children socially distanced themselves during the pandemic, n=124 (94.7%) while a small percentage did not, n=7 (5.3%).
- Children with Down syndrome had been restricted from most of their routine activities during the pandemic, traditional school (n=122/93.1%), religious activities (n=63/48.1%), therapies (n=100/76.3%), playdates and social gatherings (n=89/67.9%), community outings (n=97/74.0%), team sports (n=20/15.3%) and other (n=7/5.3%)(Table 3).
- Children's overall mood at baseline (before social distancing or the pandemic) was generally happy n=88 (67.2%).
- Almost half of the children had a change in their baseline mood (n=58, 44.3%). Of those that did experience changes, 61.2% of them were reported to be more irritable/anxious.
- Most parents reported that their children were eating as they normally did at baseline (n=95/72.5%), although almost a third (n=36, 27.5%) reported that their child did have a change in their eating habits.
- Parents reported that their children had been engaged in a variety of other activities since most routine group activities were cancelled.

Conclusions

- Most families of children with Down syndrome were following the recommended guidelines and having their children stay socially distant during the COVID-19 pandemic.
- All the children who had previously attended school outside of the home had stopped going due to school closure.
- Most of the children were unable to attend in-person therapies, along with several other restrictions and changes. Parents were forced to find other safe activities for their children.
- Changes were seen in the baseline mood of almost half of the children.
- As noted earlier, children with Down syndrome are often noted for their happy and amiable dispositions. Their social relatedness to others is often a strength. It can thus be postulated that the pandemic related social distancing has interfered with the social relationships and interactions that provided a source of happiness and fulfillment to children with Down syndrome.