Evaluating the Impact of the Covid-19 Pandemic on Families of Children and Youth from 0 to 21 Years of Age with Suspected or Diagnosed Developmental Disabilities

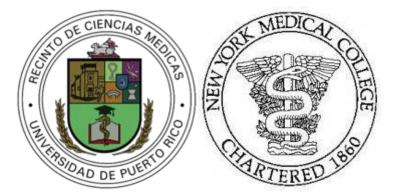




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BACKGROUND OBJECTIVES METHODS

•Covid-19 is a disease caused by a coronavirus, which had not been seen previously in humans. The virus appears as a severe acute respiratory syndrome corona virus (SARS-cov-2). In March 2020, the World Health Organization (WHO) declared Covid-19 a Pandemic. As a result of the Pandemic, in March 16, 2020, the Puerto Rico Government declared a state of emergency and a lockdown. By August 2021, Covid-19 cases declined, and the government ordered the Department of Education to reopen the classrooms and provide childcare services.

•According to the literature reviewed, the impact of loss of instructional time and related services, including mental health services as well as occupational, physical, and speech/language therapy during this pandemic period has been significant for children with disabilities. The effects of this pandemic could present a profound change in routine for these families, which can be a considerable challenge for them. The parents are also likely to experience difficulties in their caretaker role, working from home or loss of employment.

•Likewise, in Puerto Rico there is a need to research the impact of the Covid-19 pandemic to the families with children from 0 to 21 years of age with suspected or diagnosed developmental disabilities. In addition, we need to evaluate the reintegration process of educational and daycare services.

To Explore the changes that families with children from 0 to 21 years of age with Developmental Disabilities have experienced when facing the Covid-19 pandemic.

To Determine the needs that families with children with Developmental Disabilities have experienced facing the Covid-19 pandemic.

To Establish strategies to offer appropriate services to the needs of families with children with Developmental Disabilities.

Design: This study is a descriptive transversal non-experimental design.

Participants: 18 parents or caregivers with children from 0 to 21 years diagnosed or with suspected developmental disabilities.

Procedure: IRB protocol: MSC-IRB approved (Protocol B1840121).

- •Participant families who receive services in the Puerto Rico Family to Family Center administered by the Institute on Developmental Disabilities - PR-UCEDD, University of Puerto Rico.
- •Project assistants contacted the participants by phone to discuss the details of the study and schedule the interviews.
- •All participant rights and information were safeguarded.

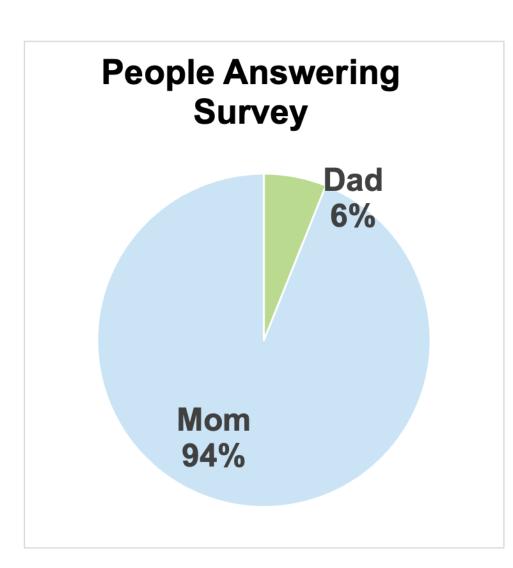
Data Collection:

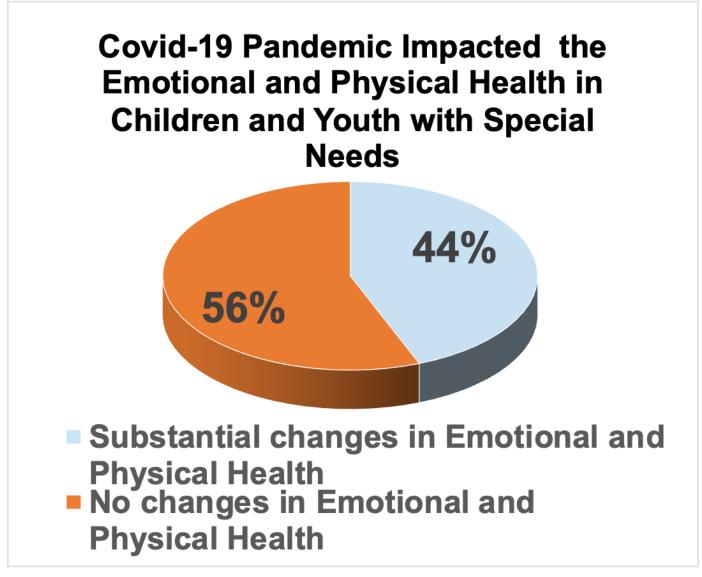
- Informed Consent Form sent by e-mail.
- •Phone interview done using a semi-structured questionnaire, which included: Socio-demographic, the impact of the Covid-19 pandemic on children with DD and their families, the availability of services, school and daycare reopening, and training recommendations.

Limitations:

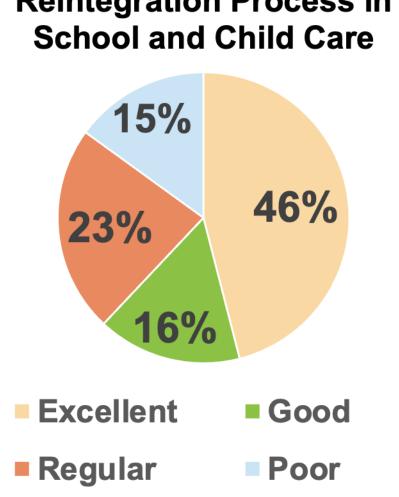
•The sample was performed by availability, and this implied that it was not representative of the entire population of families with children from 0 to 21 years old with developmental disabilities. The pandemic limited the contact and access to interview more participants.

RESULTS/PROGRESS TO DATE

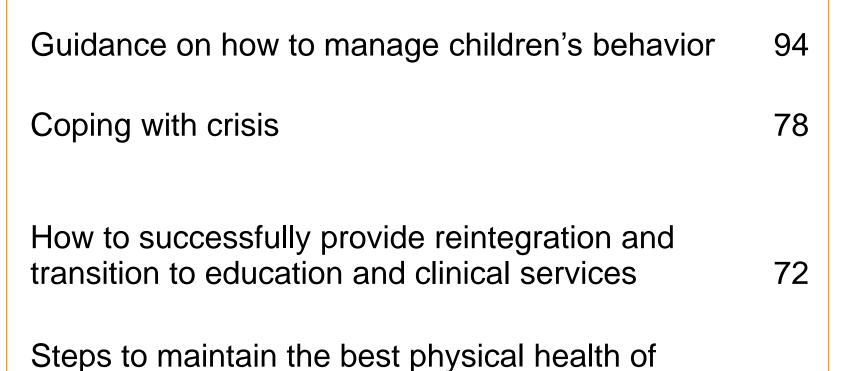








Training Topic Needs



children during a pandemic 61

Online education for children with special needs 53

OUTCOMES AND CONCLUSION

Outcomes

- ■The Covid-19 Pandemic impacted the families of children and youth who participate in the Puerto Rico Family to Family Center.
- The families reported that their main needs during the Pandemic were Emotional Support (50%), Clinical Therapies (50%), Medical Treatment (39%), Recreational Needs (33%), and Income Difficulties by Job Loss (17%).
- •Conclusion and Recommendations: This study emphasized the importance of a safety reintegration process for children and youth with special needs to daily activities such as education, childcare, recreational and social activities. It also reinforced the need to provide training in topics reported by families.