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Effectiveness of family support program on children with developmental delays

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Abstract

The aim of this retrospective study was to assess the effectiveness of the Family Support program (FSP) on children with Developmental delays in two phases. As part of Phase 1, the Developmental progress of 3 groups was investigated at 3, 6 and 9 months post the intervention. In phase 2 the effect of ages in the treatment progression (3 to 6, and 7 to 12) was studied. Sample included 101 participants in total. Significant progress was observed across all developmental stages at all 3 intervals. Age analysis found positive significant results for ages 3 to 6 and in 7 to 12, was insignificant only in the cognitive domain. Study highlights the efficacy of FSP, and illustrates significant developmental gains in children with developmental delays.

Keywords: Developmental Delay; Family; Intervention; Child Psychology; Virtual therapy

1. Introduction

Globally, one fourth of all children are suspected of having developmental delays (DD) (Gil et al., 2020). The World Health Organization (WHO) estimates that 5% of children in the world who are below the age of 15 years have some type of moderate to severe disability. Children with DD are at an increased risk for serious lifelong psychiatric conditions and behavioral disorders. However, very little is known about the origin of these issues. It is thought that the underlying causes can be multifaceted, such as environmental factors (such as, family situations), biological conditions (premature birth) or a complex interaction of these and other variables (Feldman et al., 2000); (Månsson & Stjernqvist, 2014); (Taboada et al., 2020). Some of the most affected domains of development are cognitive functions, attention, memory, communication, language, motor skills and behavioural functioning (Taboada et al., 2020; (Vasudevan & Suri, 2017). DD severely restricts children from reaching their potential without effective and timely interventions (Marlow et al., 2019). Under-identification is a major concern (Berlin et al., 1998); (Hwang et al., 2013). Identification of DD in very young children allows determination of appropriate treatments early in a child's development. Delays in diagnosis may hinder a child's developmental growth and functioning if left untreated (Noritz et al., 2013). For the purpose of this study DD is defined as a significant delay in achieving timely milestones as well developmental skill levels that are lower than the universal developmental classification based on standardized developmental profile measures.

During COVID, significant regression has been reported across most areas of functionality and life for all children, including those affected by therapeutic interventions (Kaur et al., 2006). Alarmingly, according to CDC statistics only 20% of children worldwide receive specialised mental health care (So et al., 2019).

In a survey conducted by the Indian Psychiatric Society, it was reported that there was a 20% increase in mental health disorders in India in the first week of the nationwide lockdown (Shoib et al., 2021). As a collateral effect of COVID, the uptake of tele-practices has drastically increased (Aggarwal et al., 2021).

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Telehealth intervention services make it possible to impart immediate, effective and low-cost access with fewer barriers to therapies, even outside business hours, as well as providing treatment services in remote areas. It has been found that Technology-based approaches are becoming a significant component for reducing and alleviating many of the concerns surrounding the delivery of services to vulnerable populations facing barriers to traditional services (Silva et al., 2015).

Parent training has been found to be one of the most effective methods for improving a child's growth and development (Hume et al., 2016). Parent training, as an early childhood intervention, has been found to positively affect parental attitudes, contribute to stress reduction, and increased self-confidence. When parents learn new techniques and strategies, it enhances quality of life (QOL) for them and their families (Hume et al., 2016). Family based interventions provide support with a focus on family, not just the child (Dunst & Trivette, 2009).

The FSP is a parent mediated intervention inclusive of developmental and skill-based training provided by a team of trained Psychologists assigned to all individual families, who conduct the intervention for their child. Comprehensive support is provided to the entire family based on their family and culture specific needs. A strengths-based approach is taken. Intervention is designed keeping in mind the learning style, play pattern, personality and behavioural patterns and challenges of the child. All of which is taken into account for providing clinically informed suggestions to parents. The program is supplemented by therapeutic developmental play kits that are couriered to every family. Every one and a half months one kit is dispatched with 5-6 new teaching tools in it as per child's current level of development.

The therapeutic development kits sent to parents are custom-made within the organization by clinical researchers and program experts. They have a background in psychology, especially in special education and special needs. There are different levels of the therapeutic tools that are provided, based on age-wise mapping of all the skills and sub-skills based on standardized global developmental scales classification. For every skill there are three levels – basic, intermediate and advanced. The tools are customized and sent to every individual child based on their unique intervention plan that is created by their respective child psychologist.

The objective of this study was to assess the effectiveness of a novel family support, holistic home-based program for children having special needs and developmental delays. The effects of treatment on different age groups were compared to understand if the intervention had any distinct consequence on any specific age group.

2. Methodology

2.1. Ethical approval

Ethical approval was taken from within the organization by the internal ethics committee. Informed consent was acquired by all participants. Internal ethical review was granted and sanctioned by senior most authorities responsible for ethics review within the organisation. Data confidentiality was maintained no one part-taking in research had access to any identifying information of the records, only access to required data and demographics such as age, gender, diagnostic status.

2.2. Sample

Data from 101 children (20 female, 81 male) was collected. For Phase 1, the sample was divided into three groups (Table 1): Group A (children that took intervention for 3 months), Group B (6 months) and Group C (9 months). The post-assessment was done after three months for Group A, after six months for Group B and after nine months for Group C. In Phase 2, the sample was divided into 2 groups for statistical analysis based on ages: Ages 3-6 (n=63) and Ages 7-12 (n=56).

Table 1 Gender demographics of the subjects

Intervention groups	Group A	Group B	Group C
Male (% Male)	15 (78.94%)	38 (79.15%)	28 (82.35%)
Female (% female)	4 (21.76%)	10 (20.85%)	6 (17.65%)
Total number	19	48	34

2.2.1. Inclusion criteria

Children with developmental delays in at least two areas of development were assessed.

Children showing early signs of GDD, ASD, ADHD, or comorbidities being indicative of being on spectrum, regardless of whether they met the complete criteria of diagnosis as per ICD & DSM, or not.

2.2.2. Exclusion criteria

Children who:

- were under 3 years or over 12 years of age were not included.
- had neurological disorders such as cerebral palsy (CP) or,
- those had genetic disorders or,
- as well as children who had ID comorbidities, metabolic, or neurological disorders like epilepsy were not included in this study.

2.3. Materials

Developmental Profile 3 (DP3) was used as the developmental profiling assessment tool. Developmental Profile 3 (DP3) measures development across 5 parameters, namely physical, adaptive-behaviour, social-emotional, cognitive and communication. It includes 180 items describing a particular skill with yes or no answers. The test-retest correlation for the general development score and the five scales ranges between .81 to .92 (Kuebler, n.d.). The assessment took between 40 and 60 minutes to conduct. A pre-test and post-test were conducted for each child.

2.4. Procedure

Parents or guardians of the child answered questions from the DP3 standardized questionnaire, which was administered by qualified child psychologists. Ongoing parental/guardian concerns, behavioural issues, and school related concerns were assessed by the child psychologist. Weekly training-guidance sessions were conducted with the family, to train and provide psychoeducation about the child's neurodevelopment. The set of child psychologists that were only responsible for administering and creating reports were not involved in any way in this research to minimize the scope of any bias. The sessions were conducted through audio / video calls. As a critical part of the intervention Parents were instructed to spend a minimum 30 minutes to an hour conducting intervention daily, for 5 days a week.

2.5. Data analysis

A two tailed paired samples T-test was conducted to measure progression or regression in children after the 3, 6, or 9 months of FSP intervention. It needs to be noted note that interventions delivered are cycle based with intervention time point of 3, 6, and 9 cycle ranges. The actual span of 3 months intervention cycle ranges up to 4 months, 6 months cycle ranges up to 7 months and 9 months cycle up to 10 months. After measuring progress in 3,6,9 cycle program groups, a one- tailed t test is conducted to check if the progression is a result of extensive training program or the organic development of 3- to 6-year-old children.

Another paired sample t test was conducted on the sample categorized into two age groups: age 3-6 and 7-12 to see whether there are any changes.

3. Results

The statistical analysis included a two-tailed paired sample t-test to study the effectiveness of the Family Support Program. The performance of the children at baseline and at 3 different time intervals i.e., after 3 months, 6 months and 9 months post those intervention periods respectively were compared (see Tables 2 to 4).

Table 2 Mean score and p values at α= 0.01 for Group A.

Category		**Physical**		**Social Emotional**		**Cognitive**		**Communication**		**Adaptive Behaviour**	
n		19		19		19		19		19	
Mean Scores	Pre test	20.21	-57.74%	8.94	-24.83%	11.68	-30.73%	9.36	-27.50%	112.73	-34.40%
	Post test	23.42 (66.91%)		15.78	-43.83%	18.1	-47.63%	14.05	-41.32%	17.1	-46.21%
Mean difference		3.21		6.84		6.42		4.69		4.37	
Percentage increase		9.17%		19%		16.90%		13.82%		11.81%	
Standard Deviation	Pre test	5.855		4.858		7.102		5.293		4.604	
	Post test	4.207		6.528		6.773		7.121		4.931	
Standard error	Pre test	1.343		1.114		1.629		1.214		1.056	
	Post test	0.965		1.497		1.553		1.633		1.131	
t critical value		2.8784		2.8784		2.8784		2.8784		2.8784	
t stat		-2.4756		-6.0982		-3.4327		-3.4619		-3.4815	
Df		18		18		18		18		18	
p value		0.02346		0.000009		0.002968		0.002781		0.002663	

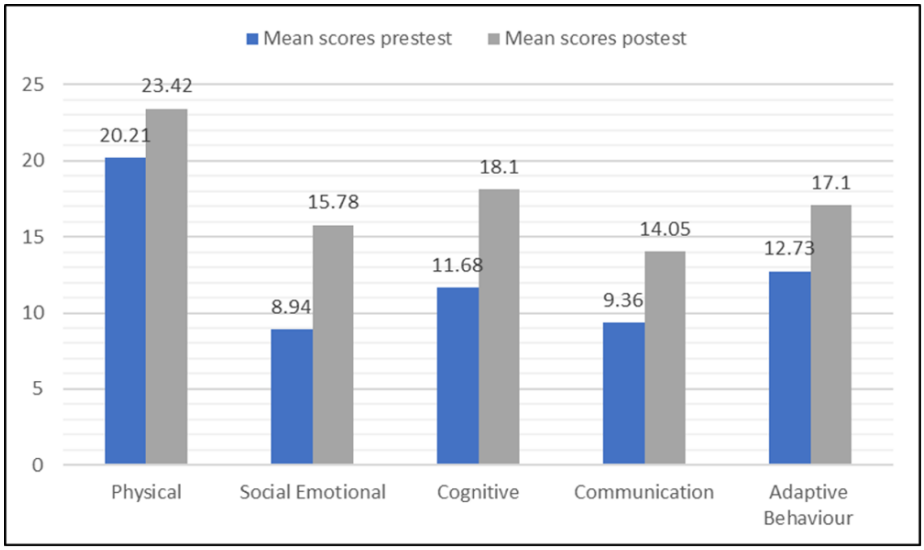

Figure 1 Difference in mean scores for all the development domains for Group A

Table 3 Mean score and p values at α= 0.01 for Group B

Category		**Physical**		**Social Emotional**		**Cognitive**		**Communication**		**Adaptive Behaviour**	
n		48		48		48		48		48	
Mean Scores	Pre test	18.89	-53.97%	8.29	-23.02%	12.79	-33.65%	10.83	-31.85%	13.83	-37.37%
	Post test	24.81	-70.88%	16.27	-45.19%	20.83	-54.81%	16.1	-47.50%	18.79	-50.78%
Mean difference		5.92		7.98		8.04		5.27		4.96	
Percentage increase		16.91%		22.17%		21.16%		15.50%		13.41%	
Standard Deviation	Pre test	6.697		5.989		9.535		7.375		6.223	
	Post test	6.449		7.972		8.511		8.244		5.903	
Standard error	Pre test	0.966		0.864		1.376		1.063		0.898	
	Post test	0.93		1.15		1.228		1.189		0.852	
t critical value		2.6845		2.6845		2.6845		2.6845		2.6845	
t stat		-5.4927		-7.1128		-5.7661		-4.1867		-5.959	
Df		47		47		47		47		47	
p value		0.000001		0.000000005		0.0000006		0.000123		0.0000003	

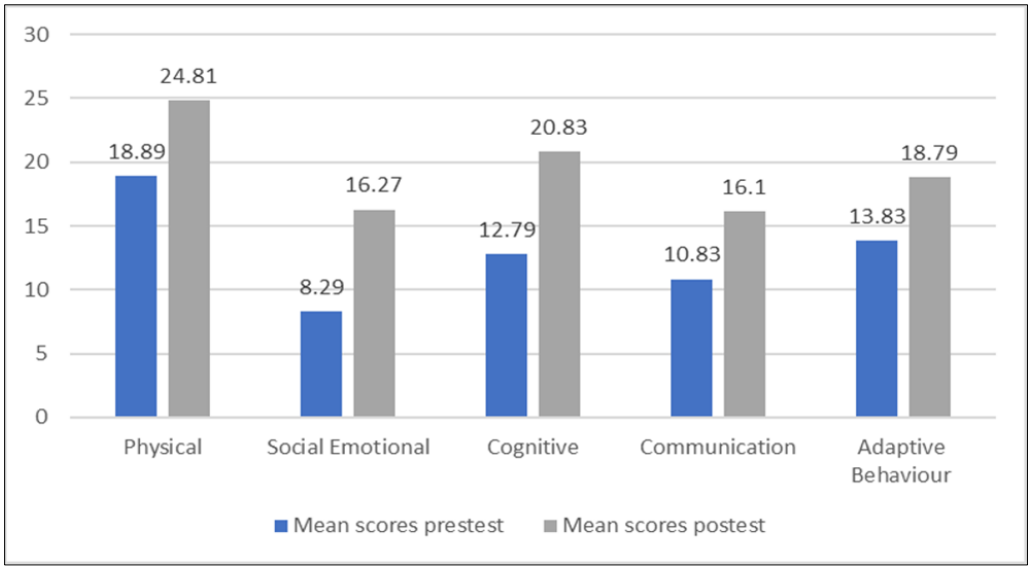

Figure 2 Difference in mean scores for all the developmental domains for Group B.

Table 4 Mean score and p values at α= 0.01 for Group C

Category		**Physical**		**Social Emotional**		**Cognitive**		**Communication**		**Adaptive Behaviour**	
n		33		33		33		33		33	
Mean Scores	Pre test	19.18	-54.80%	8.3	-23.05%	12.36	-32.52%	9.78	-28.76%	13.9	-37.56%
	Post test	24.27	-69.34%	13.84	-38.44%	20.51	-53.97%	14.54	-42.76%	18.81	-50.83%
Mean difference		5.09		5.54		8.15		4.76		4.91	
Percentage increase		14.54%		15.39%		21.45%		14%		13.27%	
Standard Deviation	Pre test	8.468		5.96		8.451		7.627		6.033	
	Post test	7.883		7.882		9.827		8.448		7.286	
Standard error	Pre test	1.474		1.037		1.471		1.327		1.05	
	Post test	1.372		1.361		1.71		1.47		1.268	
t critical value		2.7384		2.7384		2.7384		2.7384		2.7384	
t stat		-4.0115		-3.8953		-4.6208		-3.989		-4.1317	
Df		32		32		32		32		32	
p value		0.00033		0.00046		0.000059		0.000361		0.000241	

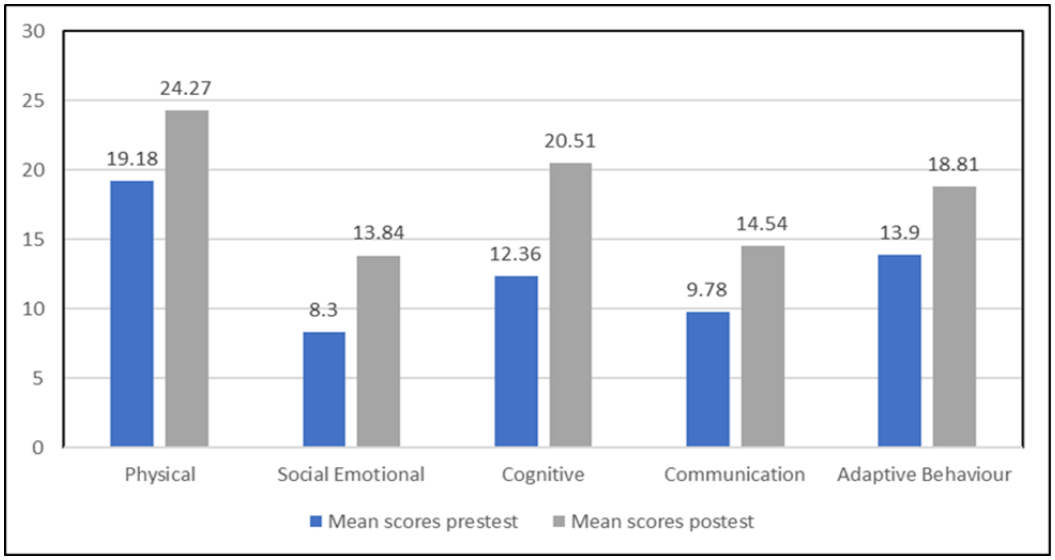

Figure 3 Difference in mean scores for all the developmental domains for Group C

Results showed an improvement in post-test scores on all domains for all three timelines from pre to post the intervention (as shown in Figures 1to 3) except the Physical domain post three months when analyzed at alpha level

0.01. This indicates that the intervention was effective in improving the functioning of the children after 3 months of intervention, 6 months of intervention as well as after 9 months of intervention.

Post assessments done after an interval of three months indicates that the FSP helped in improving the social-emotional domain the most, by 19% (Figure 4). Thereafter, it was most effective in improving the cognitive domain and the communication domain by 16.90% and 13.82% respectively. There was also an improvement in adaptive behaviour by 11.81%.

Post assessment done at the interval of 6 months shows that the social-emotional domain and the cognitive domain were immensely affected by the FSP; They both had comparable degrees of improvement of 22.17% and 21.16% respectively. FSP had an influence on the physical domain and the communication domain almost to the same degree. These two domains had an increase of 16.91% and 15.50% respectively.

Post assessment done at the interval of 9 months indicates that cognitive domain is mostly affected by FSP. Additionally, the social-emotional domain showed an improvement by 15.39%. Physical domain and the communication domain showed almost the same degree of improvement, i.e., by 14.54% and 14% respectively. Lastly, the adaptive behaviour showed an improvement by 13.27%

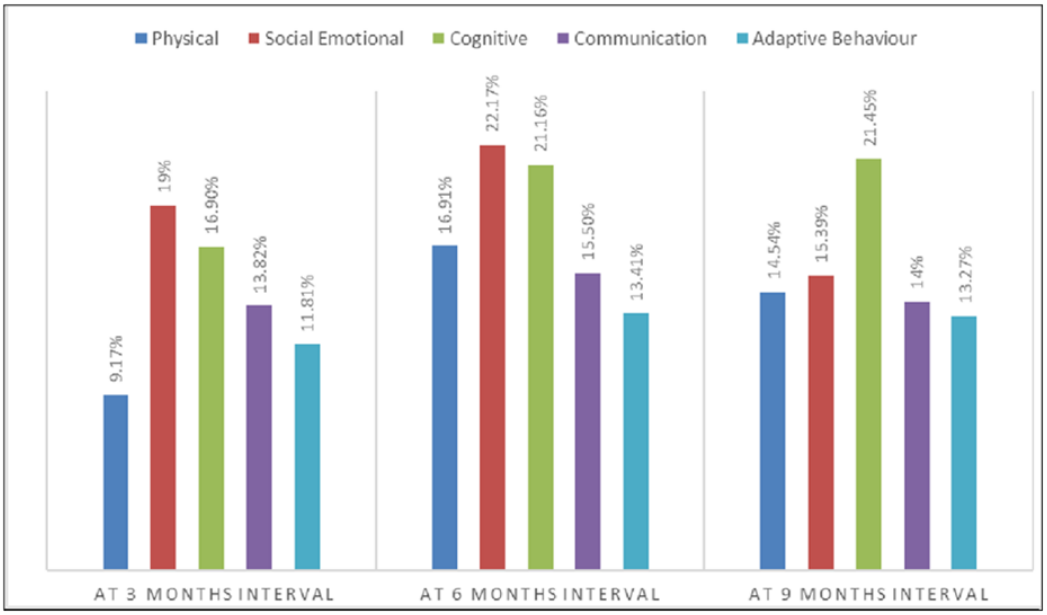

Figure 4 Percentage increase in development after 3, 6 and 9 months of intervention.

3.1. Age analysis

The statistical analysis included a one tailed paired sample t-test to study the effectiveness of the intervention to compare the performance of the children in the age range 3-6 years and 7-12 years.

For children in the 3 to 6 year age range, the measures were: physical (17.47>22.89, p=0.01), social emotional (15.63>6.63, p=0.00), Cognitive (20>8.36, p=0.00), Communication (14.78>7.57, p=0.00) and Adaptive behaviour (17.15>11.94, p=0.00) domains. This suggests that the intervention is effective in improving the overall neurodevelopmental functioning of the children at both the age groups- 3-6 years and 7-12 years.

For children in the 7 to12 year age range, the measures were: physical (26.82>20.82, p=0.00), social emotional (19.41>10.64, p=0.00), Cognitive (22.76>18.76, p=0.02), Communication (19.76>15.29, p=0.01) and Adaptive behaviour (21.82>16.14, p=0.00) domains.

4. Discussion

4.1. Phase 1

The study presents evidence that the FSP is effective in significantly improving deficits comprehensively caused by developmental delays in children of ages 3 to 12. The results also reflect lasting effects of FSP up to 9 months after the intervention.

The overall effect of FSP on the physical domain has also been found to be positive however initially little lesser than other domains. One possible explanation could be because this is not an area where parents seek to focus as an immediate priority for the most part. This makes sense considering children already showed the highest level of developmental mark in the physical domain out of all the domains to begin with.

The developmental kit of the Intervention included teaching tools for all domains, except the physical one. Activity cards were sent with the focus on physical activities. It's possible that efforts required to implement this part of the intervention were not sufficient. It took a while for parents to get acclimatized to executing the physical activities. Then once they got used to it, it picked up in progress very fast, which is evident by significantly higher gains from 3 to 6 months.

At the interval of three months (Group A), the FSP helped in improving the social- emotional skills the most in children with DD. This is not surprising, considering that initially children needed to develop softer skills through FSP such as eye contact, joint attention, understanding and responding to social cues and gestures, imitation, turn-taking, parallel play skills, sharing etc. These skills become the building blocks and core foundational abilities on which the basis for development of other skills is formulated, especially for young children and children showing deficits. This was achieved through enhancing the frequency of opportunities for positive parent-child interactions throughout the day.

The cognitive domain was also improved in Group A. Cognitive functioning is inclusive of the most basic to higher order cognitive skills. Moreover, the foundation for academic skills is laid through the progression of cognitive skills, laying emphasis on skills such as writing abilities (which most children take time to develop and are not as self-motivated to work on), counting, alphabet recognition, alphabet sequencing, upper and lowercase matching, sound and letter connections etc., laying the foundation of skills for being able to process language.

When children were tested after six months of intervention, overall, the jump in developmental gains from 3 to 6 months has been discovered to be the strongest by implementation of the FSP. At 6 months children showed the maximum improvement in the socio-emotional domain out of all domains at any time interval. It is worth noting that almost the same percentage of improvement was seen in the cognitive domain. As discussed above the socio-emotional and cognitive skills lay the foundation in terms of the developmental road map for children to then be able to build the brain architecture to be geared for linguistic and academic gains.

Subsequently, there was a major improvement in the physical domain from 3 to 6 months. The development skills in the Communication domain could be as a result of the socio- emotional gains. There seems to be a linear trend that is visible in the progression of communication skills as a result of the healthy gains in socio-emotional skills which are fostered in earliest years of children's life.

Communication skills are a cornerstone for understanding of the world, meaning- making through language. At a younger age the communication skills often involve establishing a lot of micro-skills in place that act as basis, which seem to be the socio-emotional abilities as discussed above. For example, once the child develops better eye contact that becomes more sustained over a period of time, they begin looking at the caregivers' lips for processing the formation of sounds. Hence, it is not until much later that they sync, being able to focus on auditory cues of sounds and connecting them to the formation of the mouth to produce the sounds. This may seem straightforward in neurotypical children to be picked up but is a lengthier process for children with delays. Therefore, it makes sense that the skills within the communication domain are evolving post gains in the socio-emotional domain is more established.

The post assessment done in children with DD at nine months revealed that the children showed most enhancement in the cognitive domain followed by the rest. Here, the improvements were almost showing signs of being more stable as a result of past gains, except the focus on socio-emotional skills by that point had reduced to a great degree for parents. As they are co-drivers of the intervention, in fact their wishes are highly considered while formulating goals after every 3 months of intervention.

Some noteworthy patterns are that FSP has been able to demonstrate consistent progression in cognitive domain from 3 to 6 up to 9 months. As previously discussed, the cognitive domain usually has the maximum degree of delays (Taboada et al., 2020).

There is positive improvement in physical development from 3 months to 6 months with mean increase from 9.1% to 16.1%. On the whole, the gains were maintained for the longer term, expanding the possibilities for higher development to be achieved, enhancing the potential capacity for children's life.

On the whole, the gains were maintained for some time, expanding the possibilities for higher development to be achieved, enhancing the potential capacity for the children's lives.

4.2. Phase 2

To understand the true potential of the FSP gains even better, the effect of age was also studied. The results indicated that children from ages 3 years to 6 years responded well to the intervention as they showed significant improvement in all the domains. Correspondingly, children aged 7 years to 12 years also showed significant improvement.

Early detection of Neurodevelopmental Disorders (NDD) is found to be crucial as it impacts motor, cognitive, language, learning and behaviour development with lifelong consequences (Cioni et al., 2016). This study is in line with earlier research implying the importance of early intervention in children with DD has been indicated. Moreover, the results showed how the cognitive domain might be affected if intervention is not done in the early years of the child with DD.

FSP acts as a form of preventive measure from future health complications. Delayed development has implications as that of chronic health conditions, with serious impact on families (Kushnir et al., 2008); (Varni et al., 2004).

Previous research supports that Parent mediated early language intervention programs have found significant positive effects for children with delayed development (te Kaat-van den Os et al., 2017). Multi-focal, muti-dimensional care that is family-centric, has now become an established concept for such families (Raina et al., 2004); (Ygge et al., 2006). It requires a high level of responsibility, accountability and high energy from the entire family to care for a child with delayed development (Edwards & Sarwark, 2005); (Hsieh et al., 2009).

Through FSP parents seemed to gain greater confidence and sense of control on circumstances of their child's life transforming hopelessness to hopefulness and self-belief in being able to better support their children. This to a great extent enhanced the positive attitude of parents towards FSP, which is shown by the further improvements

FSP helped in the mitigation of stress for the entire family unit and enabled healthier coping mechanisms. Research finds that different factors affecting a family having a child with disability or delays are severity of the condition, the caregiver's abilities to adapt, cope and the general levels of stress of all family members, all of which impact the entire unit (King et al., 2004); (Ygge et al., 2006). Hence the role played by the program in this regard is also another value addition.

FSP is a child-centric program as much as it is family centric. Child is kept at the heart of the intervention and the entire family unit is involved to the extent possible. An earlier study on family intervention done on the Indian population has also shown that family centred early intervention that provides education and training to the caregivers can reduce strain and empower the family (Muthukaruppan et al., 2020).

FSP has demonstrated a remarkable positive effect for the mother's psychological and physical health, which has been found to be impacted by child's behavioural challenges and demands of caregiving. Caregiver's psychological frame and overall wellbeing is affected because of caregiver demands, including practical day-to-day needs. Availability of extended support from family, neighbours, friends also have implications for health outcomes (Raina et al., 2005). Family functioning mediates stress, manages day-to-day needs of children and the needs of the family unit. Furthermore, this can support behaviour management, mitigate stress and enhance self-efficacy (Raina et al., 2005).

A child's health is affected by a confluence of varied factors such as developmental, behavioural, social, environmental, parental education (du Prel et al., 2006); (Hsieh et al., 2009). The gene-environment interaction is not just limited to development in behavioural sense of the terms but also plays a role in maturation of the neural circuits of the brain. Brain plasticity is preeminent in early postnatal periods of development and these periods are known as *critical periods.* This is representative of a complex developmental system involving a web of different brain functions. Region specific brain functions that are time-sensitive. FSP utilizes these important time-windows of opportunities from a child's early life to bring about maximum positive impact for the longer term.

Many studies revealed that early experience-environment stimuli, including parent- infant interaction, nutrition, neruo-endocrine signals all play a critical role in brain development (Inguaggiato et al., 2017). Deprived social contexts have been found to favour social development but limit cognitive development. To enhance cognitive development, active stimulation is needed. Environmental conditions improve when such interventions are in place, however what is needed is trained and staff that are domain experts to recognize and respond to needs of children and families (de los Reyes-Aragon et al., 2016). This is what the FSP intervention provides, overcoming a crucial gap in availability of trained professionals, resources as well as the scope of being able to deliver is as far reaching as can be.

4.3. Limitations

This was a retrospective design; there wasn't any way of having a control group back in time parallel to the intervention group. Moreover, at the time it was also ethically questionable and even difficult to find families that would even agree for their child to not have intervention for 3 months let alone for an extended period of up to 6 or 9 months only for research. Also, the IQ measures for the children were not tested. Efficacy of FSP would be further evidenced to know the rate of progress based on IQ variability and range for all children.

4.4. Implications

For the future, the effect of bigger sample size on the results of this intervention can be studied. Subsequently, for a planned prospective study it would be fitting to precisely quantify the time spent by parents on the intervention and its effect on the outcomes. Further, it would also be useful to have a questionnaire to evaluate the caregiver stress pre and post.

5. Conclusion

The FSP emerged as a key solution during covid times and was found to be highly effective in alleviating tremendous developmental loss, suffering of families, and reducing overall stress. FSP showed considerable marked improvement across all neurodevelopmental domains and ages between 3 to 12 years post all three time points.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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