



180Degrees  
CONSULTING  
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## 180DC SVC X PACT

### SECONDARY RESEARCH ANALYSIS REPORT

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# 1. Introduction

## 1.1) Context

Being a parent of a child with a pervasive developmental disorder such as autism, frequently associated with challenging behaviour and other complex needs, is likely to have an impact on family life and challenging experiences of parenting. In this experience of heightened parenting, emotions of frustration and guilt of being unable to fulfil the demands of your child have an extreme effect on the quality of life of parents. In order to combat this problem, residential facilities, areas where children can stay and avail 24\*7 care from specialised caretakers, have emerged as a solution. The process of sending one's child to a residential facility is a complex decision making process which involves negative emotions and hence becomes important to analyse.

## 1.2) Problem Statement and Methodology

180DC SVC was tasked to identify barriers that exist in the decision making process of stakeholders which include parents and children with autism while choosing the services of a residential facility.

The methodology followed to identify these barriers was to conduct secondary research through 10+ research papers, journal articles and dissertations.

[Click here to access the references](#). Their description is as follows:

- Reference 1: A qualitative study, involving the interviews of 8 parents who had availed services of an autism residential care facility, aimed to analyse the barriers of parents.
- Reference 2: An exploratory study, involving the interviews of 6 parents who had sent their children to an autism residential care facility, aimed to analyse the barriers for parents.
- Reference 3: Factors affecting children with autism during relocation.
- Reference 4: Description of parents' experiences of moving their autistic child between mainstream schools.
- Reference 5: A case study of a child with autism with increased psychiatric symptoms once relocated to a new residential home.
- Reference 6: Analysis of psychosocial support strategies for parents.
- Reference 7: Factors affecting children with autism in transition to new homes.



- Reference 8: Analysis of architectural issues in autism residential homes.
- Reference 9: Analysis of exercise intervention as a means of therapy for autism.
- Reference 10: The Financial Challenges of Parents of a Child with Autism.

## 2. ISSUE TREE

The barriers of entry that were identified through secondary have been demonstrated in the figure 2.1 below.

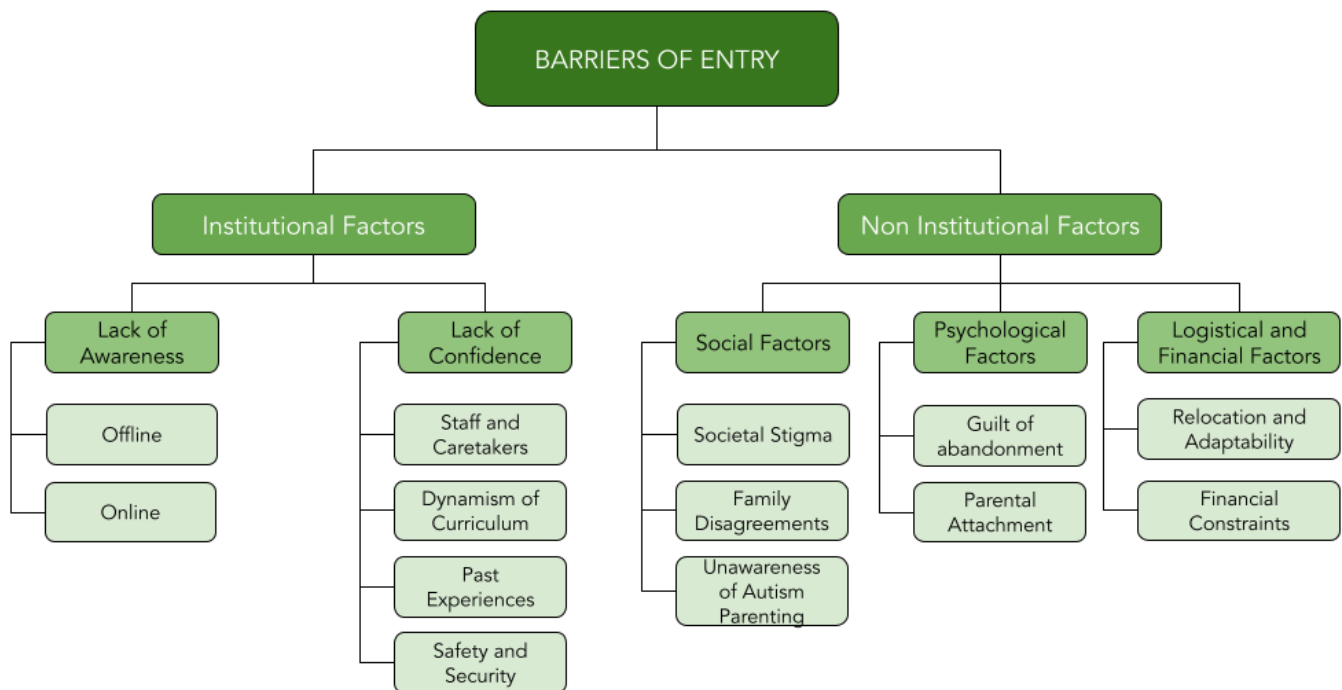


Figure 2.1



### 3. DESCRIPTION OF BARRIERS:

Click the respective headers to redirect to suggested strategies for each barrier.

S.No.	Barrier	Description
1	Institutional Factors	
1.1	<a href="#">Lack of Awareness</a>	
1.1.1	Offline Awareness	<ul style="list-style-type: none"> <li>• Lack of offline promotion in medical institutes, therapy clinics and mental health clubs, the primary autism help institutes used by parents.</li> <li>• Lack of a community network of parents where they can share their experience of autism parenting and availing services of residential facilities.</li> <li>• All interviewees in the study shared a common theme of informational asymmetry about residential institutes and how their services are an alien concept.</li> </ul>
1.1.2	Online Awareness	<ul style="list-style-type: none"> <li>• Lack of social media presence, low frequency rates and post engagement followed by poor SEO are factors which contribute to a low online presence.</li> </ul>
1.2	<a href="#">Lack of Confidence</a>	
1.2.1	Staff and Caretakers.	<ul style="list-style-type: none"> <li>• Lack of transparency over the quality of staff and caretakers lowers the confidence and trust of parents in the residential institution.</li> <li>• All interviewees in the study shared a common theme of lack of trust in the staff quality and expertise which impacted their decision severely since their child would be with the staff 24*7.</li> </ul>
1.2.2	Dynamism Of Curriculum.	<ul style="list-style-type: none"> <li>• Each parent values the uniqueness of their child and fears that it will get lost once their child gets admitted into a residential institute due to static curricula.</li> <li>• All interviewees in the study shared a common theme of fear of loss of identity of their child and their child's unique characteristics not being</li> </ul>



		incorporated into the curricula.
1.2.3	Past Experiences	<ul style="list-style-type: none"> <li>• Lack of engagement as parents in the decision making process for the child is a frequent bad past experience in the autism help industry.</li> <li>• All interviewees in the study shared a common theme of how their opinions were not being counted by the institute and they felt alienated in the entire process.</li> </ul>
1.2.4	Safety and Security	<ul style="list-style-type: none"> <li>• Lack of awareness of safety and security policies lead to a rising doubt in the minds of parents and how their child will be looked after.</li> <li>• All interviewees in the study shared a common theme of how safety and security was a foremost factor that they considered and how it was something they had to give attention to as parents while self parenting.</li> </ul>
2	Non-Institutional factors	
2.1	<a href="#">Social factors</a>	
2.1.1	Societal Stigma	<p>Parents of autistic children feel like they're being stigmatised by the people around them. This causes extreme discomfort, stress and self doubt amongst such parents.</p> <ul style="list-style-type: none"> <li>• Almost all parents of children with autism have felt stigmatised in public situations (for example at the supermarket or a shopping mall).</li> <li>• Most commonly parents imagined that others were critical of their child-raising abilities, not accepting of them and made them feel embarrassed.</li> <li>• Parents frequently noted that others didn't invite them over to their homes for social occasions such as dinners or parties or, if they did, often didn't invite them back.</li> <li>• Such reactions were often disturbing to the parents, especially when they affected the social lives of the other children in the family.</li> </ul>
2.1.2	Family Disagreements	When it comes to important decisions like enrolling their child in a long-term residential care facility, it is



		<p>common that there might be disagreements between family members who might not consider the placement as an ideal solution for the child.</p> <ul style="list-style-type: none"> <li>• Parents in the study endured unsupportive partners or spouses and indifferent family members who did not always agree on the care and long-term goals for their children and themselves.</li> <li>• This lack of agreement among family members added to the emotional and challenging decisions faced by the parents regarding the long-term care and progress of their children.</li> </ul>
2.1.3	Unawareness of autism parenting	<p>Despite the growing prevalence and awareness about ASD in India, there are still huge gaps of knowledge and awareness. Lack of understanding of their child's condition and needs hinder the parents' ability to make the right choices for their child's improvement.</p> <ul style="list-style-type: none"> <li>• Estimates of ASD prevalence have increased, but many children with autistic behaviours may not receive a formal diagnosis and parents tend to keep the matter private and defend their child from perceived threats.</li> <li>• Parents face dilemmas in deciding whether to retain the 'normal' status of the child or to seek a diagnosis for autism spectrum disorder (ASD).</li> <li>• Parents' experiences with ASD diagnosis include concerns about devaluation, stigma, and limited opportunities, as well as positive aspects such as personal development and access to resources.</li> <li>• Mothers actively defended their children from diagnosis, often adopting arguments of the anti-labelling discourse, expressing concerns about negative preconceptions and discrimination if their child was labelled as autistic.</li> </ul>
2.2	<a href="#">Psychological Factors</a>	



2.2.1	Guilt of Abandonment	<p>It is quite common for parents to feel guilty about enrolling their child into a residential organisation when they are unable to accompany them. It leads them to feel like they're abandoning their child. It stands especially true after the enrollment process is done.</p> <ul style="list-style-type: none"> <li>• Parents experienced mixed feelings of guilt, depression, and doubt after placing their children in long-term residential facilities.</li> <li>• They felt guilty, depressed, and doubtful about their decision, and expressed concerns about whether their children felt abandoned and scared after being placed in the facility.</li> <li>• Worries about whether the staff at the facility truly understood and cared for their children caused anxiety and agony for the parents.</li> <li>• Over time, the parents felt cautiously optimistic as they observed their children making progress at the facility.</li> </ul>
2.2.2	Parental Attachment	<p>It is quite common for parents to be attached to their children and hence, they usually are not happy to separate their children from themselves. Especially in the case of an autistic child where a parent perceives that their help and attention is crucial for the child it becomes even more challenging to let go of them.</p> <ul style="list-style-type: none"> <li>• The study revealed that parents expressed a strong emotional attachment to their children and initially were reluctant to consider long-term residential placement.</li> <li>• Despite initial reluctance, parents ultimately considered residential placement as a necessary step to ensure their children's overall well-being, quality of life, and long-term growth.</li> <li>• The decision-making process for long-term residential placement was emotionally challenging for the parents, with a need for careful consideration of all alternatives before choosing this (long-term residential care facility) option.</li> </ul>



2.3	<a href="#">Logistical and Financial factors</a>	
2.3.1	Relocation and Adaptability	<p>Children with autism find it especially difficult to adjust to new environments. Significant changes in their surroundings put them in a very emotionally vulnerable state. Hence parents of children with autism are highly sceptical of such a move and worry about their child's ability to cope up in such an environment.</p> <ul style="list-style-type: none"> <li>• Children with autism tend to enjoy routines and dislike changes, hence they may struggle with changes and transitions, such as moving into a new home.</li> <li>• These changes can be stressful and anxiety-provoking for them, and they may display disruptive behaviours.</li> <li>• Separation from their primary attachment figure may lead to escalation of symptoms in a child with autistic disorder.</li> <li>• Separation may be experienced as emotionally traumatic, with accompanying feelings of fear and helplessness, resulting in an increase in symptoms of anxiety and agitation.</li> </ul>
2.3.2	Financial Constraints	<p>Despite the need based financial assistance provided by PACT, the initial costs of enrollments might be a burden on the beneficiaries, especially those who belong to lower and middle income groups.</p> <ul style="list-style-type: none"> <li>• Parents incur additional and expensive costs to provide a balanced diet, cover medical therapies, and pay for extracurricular activities for their children with autism.</li> <li>• Autism may affect parents' income, leading some to resign from their jobs or work fewer hours to care for their children. This, in turn, places a significant financial burden on the parents and impacts their ability to work</li> </ul>





## 4. SUGGESTIONS AND STRATEGIES.

Addressed Issue.	Subset	Solutions	Description	Time of Execution
Lack of awareness	Offline presence	Proactive involvement	1. Social Campaign partnership with NGOs, Founder as keynote speaker for offline events and seminars  2. Sponsoring Nukkad Natak in colleges and societies with autism and residential facilities help as the primary theme	Both ▾
	Online presence	Digitally targeted Marketing	1. SEO Optimization with an excellent landing page  2. Multiple actively managed social media handles  3. Targeted ads on youtube and instagram  4. Mental health influencers and micro-influencer marketing	Both ▾



Lack of Confidence	Staff and caretakers	Familiarity and credibility	<ol style="list-style-type: none"> <li>1. Publicly accessible short video introduction of staff members to boost confidence</li> <li>2. Bi-weekly short calls by head of staff organised for the parents enrolled in the program</li> <li>3. Database with ID and contact details of staff heads on rotation</li> <li>4. Deployment of a basic app with the child's daily routine checklist and basic info updation like temperature and class behaviour</li> </ol>	Pre Admission ▾
	Dynamism of Curriculum	Leverage	<ol style="list-style-type: none"> <li>1. Unlike PACT, most autism support organisations do not have a dynamic/fluid curriculum option. So, leverage this and highlight in the marketing material on priority as a USP</li> </ol>	Pre Admission ▾
	Past Experience	Sense of belonging	<ol style="list-style-type: none"> <li>1. Make parents comfortable with a sense of community by conducting occasional meetups and organising a Parent-Teacher Association and hence involving them in key decision making processes</li> </ol>	Post Admission ▾



	Safety and Security	Transparency	<p>1. Make CCTV areas and fixate timings for broadcast so parents can view their child</p> <p>2. Install alert systems in places where a supervisor is not usually present (e.g. washrooms, prayer rooms, etc) for assistance in case of a breakdown or a mishapening</p> <p>3. GPS enabled SOS button wristbands for an even more reliable assist system</p>	Post Admission ▾
	Societal Stigma	Counselling	<p><b>Psychoeducation:</b> 1.Counsellors can educate parents about the reality of autism and dispel common myths and misconceptions. This can help parents feel less judged by society and more confident in their decision.</p> <p><b>Support Groups:</b> 1.Connecting parents with other families who have taken similar steps can provide a valuable support network. Sharing experiences and insights can help normalise the situation and reduce feelings of isolation.</p> <p><b>Advocacy Resources:</b> 1.Counsellors can guide parents towards</p>	Pre Admission ▾
Social Factors	Family Disagreement			
	Unawareness of Autism Parenting			



Psychological Factors	Guilt of abandonment	Counselling	<p>resources and organisations that advocate for the rights and needs of autistic individuals. This can empower parents to overcome external pressures and stand by their decision.</p> <p>Exploration of Separation Anxiety: 1.Counsellors can help parents understand and address their own separation anxiety, which can mirror their child's anxieties. This can help them cope with the emotional challenges of the separation.</p>	Pre Admission ▾
	Parental Attachment		<p>Maintaining Connection: 1.Counselors can encourage parents to develop strategies for maintaining a strong connection with their child, such as regular visits, phone calls, video chats, and exchanging letters.</p> <p>Coping Mechanisms: 1.Counsellors can provide parents with healthy coping mechanisms for managing stress, anxiety, and grief related to the separation. This can help them maintain emotional well-being and continue providing loving support for their child.</p>	

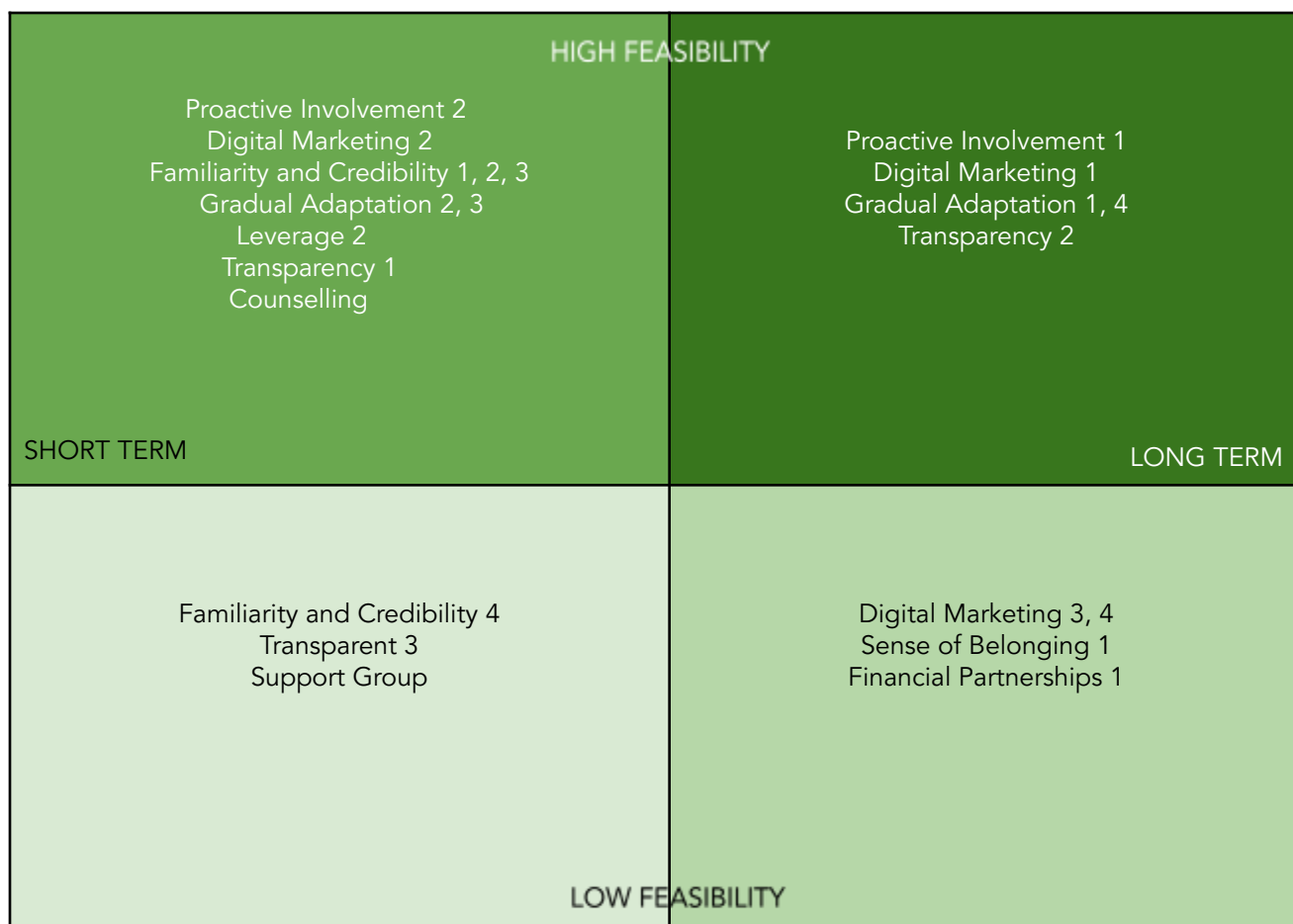


Logistical and Financial Factors	Relocation and Adaptability	Gradual Adaptation	<p>1. PACT should send pictures of specific parts of the facility to get the child familiar with the environment before admission.</p> <p>2. PACT should get the parents to visit the residence, and have a professional team which can work in collaboration with the families to alter some spaces in the residence according to their child's needs. This team should also assist in packing and moving.</p> <p>3. PACT should make the child love the new experience by having him have their favourite things around, food for example. They should let the new house seem to magically come with loads of rewarding surprises.</p> <p>4. There should be a comprehensive onboarding plan including involving specific activities to feel involved, introduction to caretakers, information of safety provisions.</p>	<div>Pre Admission ▾</div>
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			5. To reduce separation anxiety, there should be higher parental involvement in their curriculum in the beginning which can be gradually reduced.	Post Admission ▾
	Financial Constraints	Financial Partnerships	PACT can look to partner with small finance banks to offer lower interest rates for parents who take loans for their children's admission to the facility.	Pre Admission ▾

## 5. PERCEPTUAL MAP OF STRATEGIES



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