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KAIRAVI DEY

Jai Vakeel Foundation: Addressing Disability

In April 2019, as the end of the academic year approached, the Jai Vakeel Foundation campus in Mumbai was abuzz. It was their 75th year of supporting children with intellectual and other disabilities. Archana Chandra entered her office after a busy day of meetings with students and her teaching staff. Rishit's parents who were sitting patiently outside, immediately arose on seeing her, and with folded hands (which is customary in India) thanked her profusely for giving them hope. Four-year-old Rishit, had entered Jai Vakeel two years ago soon after being diagnosed with Down Syndrome. At that time, he had been unable to sit or stand or use his hands. Rishit could now walk and drink water all by himself. Even while acknowledging the gratitude of Rishit's parents, Chandra could not help thinking about the fate of millions of other children like Rishit whom Jai Vakeel was hardly able to reach.

Jai Vakeel Foundation and Research Centre (Jai Vakeel) was a non-profit organization working towards improving the lives of persons with intellectual disability (PwID), largely from low-income families. Established in 1944, it was run by the founding family until 2013, when Chandra took over as CEO. The biggest challenge facing Chandra and her team had been staying true to the philosophy of the founding family while addressing the question of sustainability and scaling the work of the foundation. She and her team had considerably evolved the overall direction of the foundation, helping Jai Vakeel emerge as the largest organization of its kind in India by 2019.[1] It served nearly 800 students directly with a staff of about 200 persons (of which 140 were special educators & caretakers) and an expense budget of Rs. 10 crores ($ 1.6 million).[a] Jai Vakeel also served an additional 2000 students through their two rural medical camps every year. There were, however, millions more children who lived with intellectual and other associated disabilities across the country, with no access to healthcare, therapy or skill development services. Chandra wondered whether they were ready to scale, and if so how? If not, what else should Jai Vakeel do to earn the right to scale?

Intellectual Disability

Intellectual Disability (ID) is a significant limitation in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. It is a condition, not a disease, originating before the age of 18. Such persons had difficulty in learning, understanding,
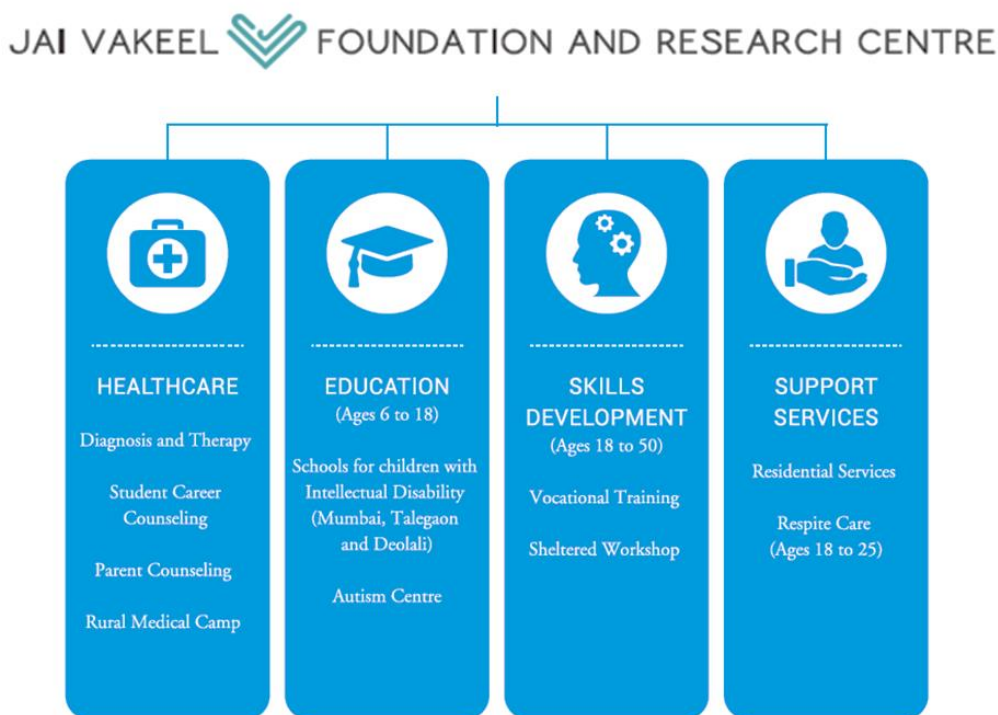
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[a] 1 USD = 70 INR

communicating with others and adjusting to various situations in day-to-day life. The IQ test had been used as a major tool in measuring intellectual functioning, which was the mental capacity for learning, reasoning, and problem solving. The severity was classified from mild (IQ below 70 to 50), moderate (IQ from 49 to 35), severe (IQ from 34 to 20), to profound (IQ below 20).[2]

Children with this condition often faced discrimination and humiliation because of their inability to keep up with their peers. As these children grew older, they faced stigma and were considered unfit for higher education and employment.[3] By some estimates an astounding 2% to 3% of India's population of 1.3 billion people (350 million below the age of 14) were said to be afflicted by this disability. In an effort to address this issue, in 2016 the government of India passed the 'The Rights of Persons with Disabilities (RPwD) Act.' It recognized 21 categories of disabilities, compared to the 7 categories previously identified. It also adopted a holistic approach to disability rights and recognized the social, economic and political rights and freedom of people with disabilities.[4]

Many non-profit organizations across the country served in this space. Jai Vakeel, with a corpus of about Rs.19 crores ($2.7 million), was the largest and oldest of these. It had four major service pillars as shown in **Figure A** below. (See **Exhibits 1A and 1B** for details of the services under each pillar, and **Exhibit 2** for the number of individuals served**.**)

Figure A Jai Vakeel's Service Pillars

JAI VAKEEL ❤ FOUNDATION AND RESEARCH CENTRE

HEALTHCARE	EDUCATION (Ages 6 to 18)	SKILLS DEVELOPMENT (Ages 18 to 50)	SUPPORT SERVICES
Diagnosis and Therapy	Schools for children with Intellectual Disability (Mumbai, Talegaon and Deolali)	Vocational Training	Residential Services
Student Career Counseling		Sheltered Workshop	Respite Care (Ages 18 to 25)
Parent Counseling	Autism Centre		
Rural Medical Camp			

Source: Company documents

Other notable organizations were the Action for Autism (New Delhi), the Bethany Society (Meghalaya) and The Indian Institute of Cerebral Palsy (West Bengal). More recently, a number of

special schools had also emerged: The Aditya Birla Integrated School and the Gateway School catered to the more affluent, relatively higher functioning children. "The big differentiator between Jai Vakeel and the others," explained Anjali Sabnani, head of communications at the Jai Vakeel Foundation, "was that all of Jai Vakeel's offerings were in one physical space."

The Evolution of Jai Vakeel

The Beginning

The organization was founded in 1944 by Mr. Hormusjee and Mrs. Jai Vakeel with a simple goal to help their daughter, Dina, who was diagnosed with Down's Syndrome. The goal was to get her the education, therapy, and encouragement that she needed at home to live as normal an existence as was feasible under the circumstances. They then expanded to a 2-acre campus in Mumbai with the aim of helping children in and around the city, who were born with similar conditions.

Dina's sister, Tehmina Shroff, regularly visited Jai Vakeel since her early childhood. She grew up being deeply attached to her sister and committed to the cause of intellectual disability and was driven to improve the lives of the children who lived with this condition. In 1980, after her mother's death, she took over the responsibilities for running the foundation. For those who knew her, it was her hands-on and empathetic style of leadership that stood out. She was described by her staff and volunteers as the 'mother figure', a visionary who worked tirelessly to build the institution's capacity to care for every child in need.

Establishing the Guiding Philosophy

Since the beginning, the ideology that guided Jai Vakeel's work was to accept every child who needed help and never say no to anyone in need, regardless of the complexity of the case or their socioeconomic background. It was this unrelenting commitment that made Jai Vakeel unique. Most other centers in the ID space had restrictions or selection criteria for enrollment but Shroff believed the need of the child should be at the center of every decision; she ensured this belief was enshrined in the values of the institute, which was stated as: *Everyone is entitled to a life of dignity. Do not look at their disability, let's build on their ability.*

As a result, 90% of the children at Jai Vakeel had multiple disorders and 70% were from low income families. They had nowhere else to go and were referred to Jai Vakeel as a last resort. The organization grew organically and slowly over the years to become a one-stop shop for all the needs of the PwID (Persons with Intellectual Disability) throughout their lifetime.

Chandra Joins Jai Vakeel

Archana Chandra began her career in the corporate world: at Bennett Coleman and Company Ltd, a media conglomerate and then at Informix, an IT company. Exposure to their large-scale events sparked her interest in event management and helped build her communication and PR skills.

In 2001, with Informix ceasing its Indian operations, Chandra found herself at a crossroad with respect to her career. She was uncertain whether a corporate career was what she sought. At the time,

a friend, from the Akanksha Foundation[b], inspired her to enter the non-profit space. Chandra was drawn by her friend's motivation and energy to take a step forward.

Chandra began volunteering at Akanksha; an institution that eventually became her training ground for a career in the non-profit sector. Shaheen Mistri, Akanksha's founder, eased her into the non-profit space by tapping into her strengths in PR, marketing and communications. Chandra became an effective fundraiser for Akanksha until one day its founder surprised her by asking her to also take on the HR function, thus began Chandra's induction into nonprofit leadership. While enjoying the new challenges that her foray into the nonprofit sector brought her, she later chose to take a couple of years off to raise a family.

And then one day out of the blue at a social event in 2007, Chandra met an old friend, Dr. Anahita Pandole, a renowned gynecologist. Pandole, who was also a friend of the Vakeel family, insisted that Chandra visit the Jai Vakeel campus to experience the remarkable work being done by this organization's inspirational leader, Shroff. Chandra at that time knew very little of Jai Vakeel's work but nonetheless took up her friend's offer. She recalled, "As I walked around the Jai Vakeel campus, I was struck by the positive energy on the campus despite all the difficulties." The spirit of the students, staff and volunteers touched Chandra's heart. She observed, "In spite of what we know to be the real numbers, we don't see these children anywhere in our daily lives, whether it is at the movies, the malls or the theaters or any social places. They seem to be hidden away. That's how my head got engaged."

By 2008, Chandra and her spouse had made a financial donation to the organization and she was spending more and more time volunteering at the Jai Vakeel Foundation. "It would be fair to say that the place found me rather than the other way around. I found a space so underserved that nobody even understood the term intellectual disability outside the four walls of the foundation. If I was going to spend my time and effort somewhere, I was happy to invest it in a place that desperately needed a spotlight," she reminisced. Encouraged by Shroff's confidence, Chandra took on significant responsibilities in the organization. She was motivated to make a difference.

In addition, borrowing a page from her PR and marketing expertise, Chandra initiated the organization's first formal fundraising event, called *Confluence* in 2008. Until then, much of the fundraising had been informal from Shroff's friends and family who gathered in her living room for tea, often when the organization was running out of funds.

Changing Board Dynamics

At the end of her first-year of volunteering at Jai Vakeel, Chandra was invited by Shroff to join the foundation's board. Until then, the board had comprised of family and friends of the founding family. It included Shroff's daughter Zia Cama and her son, Pesi Shroff (Pesi). It was Shroff who made all the important decisions for the foundation and kept the board members informed. Reflecting on Shroff's decision to induct Chandra as a board member, Pandole remembered, "Archana was taking no salary or compensation, her integrity was beyond reproach. She had shown us how competent she was through her ability to solve problems and was willing to do whatever it took to actually make a difference in our children's lives. That's how I think the trust was built."

Chandra's induction into the board in 2009 was the harbinger of further changes to the board. Pandole and leading pediatric neurologist, Dr. Anaita Udwadia Hegde were also appointed to the

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[b] The Akanksha Foundation was a non-profit organization providing children from low-income communities a high-quality education, with the aim of maximizing their potential.

board in the same year. In 2011, RK Kasliwal from the Aditya Birla Group[c] and in 2015, renowned investment banker, Vedika Bhandarkar, who had been a volunteer for a year, were also appointed as board members.

Fundraising

Now as board member, Chandra began to formalize the fundraising drive and following up on the first one she had organized two years ago. She initiated fundraising events *Treasure Trove 1* in 2010 and *Treasure Trove 2* in 2012. Credit Suisse's CEO in India, Mickey Doshi and his wife attended Treasure Trove 2, taking the time to understand the work of Jai Vakeel. Like most visitors, they too were deeply touched by what they saw. Doshi and his wife went on to raise funds for Jai Vakeel through the Mumbai marathon in 2014 and 2017.

Until then the foundation's finances were often hand-to-mouth. (See **Exhibit 3** for the organization's financial history.) Most of the organization's funding came from government sources. With the organic expansion of the services being offered, the foundation had drawn down a considerable portion of its finances. It was becoming increasingly difficult to run operations. Chandra realized they needed to diversify beyond government funding. As part of Jai Vakeel's funding strategy, Chandra began reaching out to corporations and inviting their key decision makers to the campus to gain first-hand knowledge of the foundation's work.

Fortuitously in 2013, the Indian government amended the Companies Act; every large company was now mandated to spend 2% of their net profits on corporate social responsibility (CSR) projects. [5,6]

Seizing the opportunity, Chandra's team reached out to Credit Suisse. Doshi, having seen for himself what his initial donation could do, made a large grant of some $250,000 (Rs. 15 million). "Credit Suisse was one of the first corporations to support us in a big way, because their CEO had seen our challenges and our journey," Chandra recollected. "Those two or three events opened the doors for us in the subsequent years and helped us stabilize our private fundraising," she observed. (See **Exhibit 4** for Jai Vakeel's funding history.)

The Call for a CEO Succession Plan

In 2010, Farhad Sutaria, a philanthropist and family friend of Dr. Hegde, approached Jai Vakeel's board with a promise of substantial support. He spent a few days on campus understanding the organization and its culture and suggested that Shroff formulate a clear succession plan, so he would know that a substantial gift would have benefits well into the future. But Shroff balked; she did not believe in creating a succession plan. She was confident her children would keep the foundation running after she was gone. Her daughter Cama remembered, "I don't recall my mom pushing any of us to take over. I was very clear that I would never actually run the school, but I knew that I would always be there for Jai Vakeel; (Pesi and I) always had the school at heart. But we were not like my mom, for her the school and the children were her life. That was not the case for me or my brother. We both had a busy professional life outside of the school."

During those "turbulent times" when obtaining funding was critical, Chandra and the more recent board members, did their best to persuade Shroff of the merits of creating a succession plan. After numerous discussions, they approached the founding family and their friends on the board. Chandra recalled her conversations with the family, "They told us Jai Vakeel was Shroff's entire life. This was

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[c] The Aditya Birla Group was a large Indian conglomerate and a significant contributor to Jai Vakeel's funds.

her reason to get out of bed, every single morning, no matter her age or her health and if we take this away from her, then we will be taking away her will to live." The board chose to forsake the funds in favor of continuing with Shroff at the helm.

Shroff had given herself the title of administrative director and named Chandra as the joint administrative director. She used to jokingly say to the board, "Why are you all worried? If none of my kids step forward, Archana (Chandra) is always here."

In 2013, Shroff's health began to deteriorate, but she continued to visit the school, spending about 10 hours each day there. In August she had a fall and was hospitalized. A few weeks later she passed away. She was 83 then and had run the organization for 39 years.

Passing the Torch: Archana Chandra becomes CEO

Jai Vakeel had grown organically and made a name for itself in the development community. As the newly constituted board began to dig into the finances and the organization's capabilities, doubts about its sustainability going forward loomed large. The board thought such strategic issues could no longer be ignored. Given the leadership initiatives that Chandra had displayed, without much delay, the board unanimously appointed Chandra as the new CEO.

Designing a New Strategy: From Care to Inclusion

On taking over as CEO, Chandra decided that the organization needed a serious outside-in perspective. She started to tap her network to identify top professionals and volunteers to help her and her team plot the future of Jai Vakeel. "Mrs. Shroff used to pride herself in saying that we serve the children from the womb to the tomb, but the lens through which we designed the strategy for the future needed to evolve," Chandra observed. "We asked ourselves, is this enough or should we be doing more?" Chandra recognized the overwhelming task of carrying on the legacy of the founding family, which had run the organization for over 60 years. Until then, Jai Vakeel had grown organically, mainly driven by the aim of caring for the children. However, its finances were under severe strain. Jai Vakeel's treasurer, Rajendra Kasliwal had gently cautioned Chandra, "Archana, if you continue with the practice of cashing-in on fixed deposits like in the past, you will have to shut Jai Vakeel down within 3 years," Chandra decided to prioritize improving and stabilizing Jai Vakeel's finances. Ravi Venkateswar, a corporate veteran with over 30 years of experience in finance across various multinational companies, offered to volunteer at Jai Vakeel and conducted a thorough assessment of the foundation's financial sustainability. (See Exhibit **5** for the changed composition of the Jai Vakeel board from 2007 to 2018.)

In parallel, starting in 2014, Chandra initiated a process of reassessing the organization's mission, vision and strategy. "I inherited a great organization doing unbelievable work, but the board and I thought the transition would provide us an opportunity to take a step back and re-evaluate what we were doing. What problem were we trying to solve? For whom? What activities would we have to engage in to solve that problem? How would we know whether we were successful?"

Two other volunteers, Priya Agarwal and Enma Popli helped Chandra lead a strategy and visioning session. Agarwal had 17 years of experience in the social sector and Popli was an HR professional with a decade of experience in corporate HR. At every session and stage of the process, the staff, the leadership team and the board were part of the conversation. Every stakeholder's voice was heard, including not just the board and staff, but also parents and funders.

As a result of the re-visioning process, Jai Vakeel's overarching philosophy evolved from simply 'caring' to 'caring with a goal of inclusion in the community'. The vision was reframed: *To strive for the inclusion of the intellectually disabled by maximizing their potential.*

Winding Down the Non-Core Programs

The process of identifying Jai Vakeel's core competencies, meant that non-core programs that didn't make it to the short list, were identified as well. There was serious internal debate as to how Jai Vakeel should manage the non-core activities. Eventually, Chandra and the board made the difficult decision of closing down those activities. "We simply did not have the resources or the competencies to sustain excellence in our non-core programs," said Chandra. "Instead, it was decided that we should seek partners who were better at those activities than we were. While I knew that the refocus and the decisions were necessary, it was by no means an easy task. It brought about an upheaval in the organization and was met with fierce resistance from the staff, especially those who had been in the organization for a long time." The following programs came under the axe:

The Residential Section: This was started in 1952 to address the needs of children who were either orphaned, abandoned, or whose parents were unable to travel from their homes to the institute on a daily basis due to mobility and other constraints. The residents were all younger when the section was started; but by 2014, their needs had significantly evolved—they required more medical and nursing needs, which Jai Vakeel was not equipped to provide. The board and the senior leadership team decided to wind down the residential section and move the affected students to external residences catering to individuals with special needs. One such place was Adhar Homes, a residence providing lifelong care, training and rehabilitation facilities to people with ID.[7] Chandra and senior colleague Chetna Bhatt (head of the residential section) visited and verified for themselves that the Adhar residences would provide appropriate support for their children.

Over the next few years, Jai Vakeel transferred 35 of their 37 students to partner residences. The team raised funds for each child and paid Adhar a one-time upfront fee for life time services. It however decided to continue housing two children at its campus. These children, Gauri and Noorbanu, were profoundly intellectually disabled and had multiple physical disorders. Jai Vakeel employed a full-time caretaker to help and support these children.[d]

Blood Test Laboratory: This was started in 1974 to provide a comprehensive diagnostic resource to the families of the children at Jai Vakeel. The labs conducted genetic and metabolic testing. Over time, as technology improved, newer diagnostic centres providing more technologically sophisticated versions of these tests appeared. Jai Vakeel decided to close its own laboratory and collaborate with one of the newer diagnostic chains, Metropolis labs. Jai Vakeel's children could now complete their tests at subsidized rates at Metropolis Labs.

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[d] Gauri had been abandoned on the streets of Mumbai city in 2010 soon after she was born. Her eyes had been gouged out and she was unable to walk or move her limbs. When she was rescued and brought to Jai Vakeel, no one knew her history or her family. Diagnosed with spastic diplegia cerebral palsy and profound intellectual disability, she was fed liquids through a tube in her nose. Nine years of medical care, intense therapy and caregiving by a personal caretaker had made Gauri visibly stronger. It was, however, impossible for her to leave the Jai Vakeel campus as she required constant care and support. Her personal caretaker, Mumtaz, never left her side, "My bond with Gauri is special, she is like my own daughter. She brings out the best in me."

*Teacher Training College***:** was started in 1952 to address the shortage of trained special needs educators. It was the first of its kind. However, over time, the landscape had evolved and other organizations focusing on teacher training courses had emerged. In addition, the University requirements had evolved, and Jai Vakeel needed to invest more resources and capital to continue running the Teacher Training College. Hence, in 2014, Jai Vakeel decided to close the college and focus on its other core activities.

Restructuring Respite Care

In addition to winding down the non-core activities, Jai Vakeel restructured the services it delivered through its Respite Care program. Started in 2014, Respite Care, was a seven-year program to help those with severe to profound ID between the ages of 18 and 25.[8] The goal was to make them comfortable in managing day-to-day activities. As Dilip Kurani, a senior occupational therapist, described, "It was intended as *respite* more for the families of these individuals," as it would free up time for their families to engage in other activities, possibly take up part-time employment to increase the household income. At the end of 7 years, at the age of 25, the individuals were to retire from Jai Vakeel and go on to live more independent lives, with improved abilities. The families of these students were initially content as this program provided them support and relief. They were, however, completely against the decision to set the retirement age as 25, as they felt they were being abandoned by the institution that under Shroff had promised to always take care of them.

The decision to restrict the retirement age to 25 had serious implications. The families of the affected individuals took the Jai Vakeel team to court as they felt they had been "cheated." The judge didn't register a case, instead he gave both sides an opportunity to share their perspectives and helped them mediate a settlement. Chandra explained, "The fact remained that if we kept them for longer, we would not be able to help the next child who is younger and in need of the same service." They finally agreed on a two-year transition period during which the Jai Vakeel team would provide complete support to the families.

The team decided to scale fundamental elements and partner with organizations for the non-core elements. They believed these partnerships would help Jai Vakeel improve the quality of its services and focus on building on their strengths. In Chandra's words, "We were attempting to shift from providing services to building a center of excellence on the campus." Under Chandra, Jai Vakeel had forged numerous partnerships for non-core services. She was hoping to continue the trend. (See **Exhibit 6** for details of partnerships.)

Changing the Organizational Decision-Making Structure

Chandra reached out to Popli to help her design an effective organization to deliver the new plan. Offering her services as a volunteer, Popli conducted an HR audit and made some significant recommendations on running the organization. Based on that, Chandra and Popli drew up a new organization structure. (See **Exhibits 7A and 7B** for the old and the new organization structures.)

During Shroff's tenure, the functional heads were focused on executing the strategy and vision that Shroff had laid out. They did not participate in developing Jai Vakeel's vision or long-term plan. The organization structure was flat with all the functional heads and even members of staff and volunteers bringing their concerns and issues directly to Shroff. Of course, not all this was bad as Popli observed. It had some distinctive advantages. The open-door policy which allowed everyone to approach the CEO directly and Shroff's hands-on style ensured that everyone pulled their weight to attend to the

needs of the individual child. It was like a family. Popli noted, however, that the organization was highly centralized, diminishing the agency and accountability of the functional heads.

The new structure meant that teachers, staff and volunteers, who had been free to walk into Shroff's office to discuss any issue, were now guided through functional heads, before they could access the CEO's office. Filling the functional head positions was not easy, but nonetheless important for the integrity of the organizational process going forward. The staff initially saw this as unnecessary and did not like the "wall" between them and the leadership. It took them a while to get used to the hierarchy.

In 2009, Jai Vakeel had 165 staff members and 10 volunteers. By 2019, the organization had expanded to 226 staff members and about 64 volunteers, including several senior advisors like Popli. Prominent among them were Neha Shah, Sangita Singh and Anjali Sabnani.

Shah was the head of the vocational training center before moving on to lead operations and special projects; she played a significant role in the implementation of the new strategic initiatives. Singh, with an extensive background in manufacturing, went to lead the organization's skill development and vocational training center. Sabnani had many years of experience in education and went on to lead the organization's marketing and communications function. Popli led the organization's HR and staffing function. Although she had moved to a different city in 2015, she continued to mentor the HR department and work closely with Chandra on HR strategy and employee engagement.

Moving Forward with Confidence

"None of these decisions were easy to implement even though I knew in my heart that we had arrived at them through a rigorous process," recalled Chandra. She pointed to a non-profit leadership course she attended at the Harvard Business School (Strategic Perspectives in Nonprofit Management) that gave her the resolve to press ahead. "I heard lectures that advanced the idea that strategy was about choices including about what organizations should not do, and to be unapologetic about it. I heard lectures on "thinking out of the box," and how each leader would have to calibrate their own leadership style. All this gave me the confidence that we were on the right track to evolving our organization for a better future," she observed.

Chandra believed that over time non-profit organizations in India had developed a reputation of being 'sympathy-seeking and submissive,' spending relatively frugally on promotion, marketing and technology and she was keen to challenge this mindset at Jai Vakeel. She aimed to establish Jai Vakeel on par with better known NGOs in India. Starting at the grassroots level, she improved the quality of promotional materials, changed the tone of communication and began addressing corporate donors as partners.

Chandra's team identified the core aspects of Jai Vakeel's services and took measures that explicitly aimed to integrate the children into mainstream society to implement them, The idea was to focus attention and resources on identifying and improving core aspects such as education (curriculum), skill development, healthcare (individualized therapy), and at the same time, initiating efforts to actively engage with the community and sensitize people to the cause of ID.

Developing a New Curriculum

Leveraging the knowledge and experience it had gained over the years, the Jai Vakeel team decided to develop its own curriculum as no standardized curriculum in this sector existed. Developing this

took several rounds of experimentation, and in the 2016-2017 academic year, they rolled out a new curriculum at the primary level that included subjects such as English, math, science, environmental studies and activities of daily living. This was aligned to their new philosophy of inclusion, that is improving social behavior and helping children learn skills to lead a dignified life**.**

The curriculum, the first of its kind, was built using multisensory teaching methods and was designed to promote learning in a relevant, meaningful and enjoyable manner, bearing in mind the uniqueness of each child's pedagogical requirements. Deepti Gubbi, the head of the education vertical explained, "Each child has the ability to learn; we just needed to teach in a way that allowed for it. Inclusion is the right of each child and through this curriculum, we hope to facilitate that and set a standard of excellence."

Chandra's team signed an MoU with the Maharashtra (state) government and hoped to gradually extend this syllabus to 187 schools across the state.[9] Chandra was aware of the challenges where impact and consistent growth were the priorities. While the curriculum was developed with the aim of promoting learning for each child, a single seizure could cause a child to drastically regress. These factors were outside the control of the team and had to be accounted for.

Chandra was also keen to create an MIS system to manage the data they had collected on diagnosis, intervention, and outcomes for hundreds of children. The goal was to track the progress of each child, maintain data accuracy, and save time for the medical practitioners and therapists. Shah, the head of Special Projects, described the need for the system, "We had collected a tremendous amount of data over the last 50 years, but the physical files didn't allow for aggregation of this data to capture the true outcomes of the children. We were therefore seeking a more robust system approach."

Since building this system was an expensive and time-consuming process, Chandra approached the team at Edelweiss, a financial services company with a rich culture of skilled volunteering, through their philanthropic arm, EdelGive. Edelweiss readily agreed to provide the resources to build the system and share the cost of the database. A team from Edelweiss worked with Shah to identify Jai Vakeel's requirements and build the online platform *Oyster* for recording, storing and tracking health and education data of each child with ID, the first of its kind in India.[10] Over time one of the key members, Sandeep Bhandarkar, grew more devoted to Jai Vakeel and agreed to be an advisor to the leadership team. (See **Exhibit 8** for details of Oyster).

Improving Skill Development

Jai Vakeel's 3-year vocational training program was designed to help students above the age of 18 develop skills, build self-esteem and become independent and contributing members in society. The skills taught depended on the ability and aptitude of the students, and included weaving, sewing, making paper products and candles.[11] Upon completion of this 3-year program, those who didn't qualify for outside employment were placed in the sheltered workshop within Jai Vakeel, where they made these products and were paid a stipend based on their productivity. The board and Chandra's team decided that the retirement age for the sheltered workshop should be 50; they also reduced the number of vocations from 11 to 9. They focused on improving the quality of the products and increasing the productivity of children in their chosen vocations.

Sangita Singh led the skill development section. Having worked with manufacturing and export companies for 22 years, she could identify gaps in the sheltered workshop processes and identify ways to improve efficiency. "Every time I approached the CEO with feedback on the current operations and a new idea to improve the situation, I was supported to bring about the change. Creating this open platform was key; I felt committed and responsible," Singh remembered.

In 2019, with 230 individuals, the Jai Vakeel skill development center was the largest of its kind in India; the total sales from the sheltered workshop were Rs. 6.2 million ($89,000). Chandra explained, "The bigger objective for that department is to become self-sustainable. We were working more towards financial inclusion in the family as opposed to merely giving the individual a stipend." Their aim was to reach sales of Rs. 10 million ($142,875) by 2020.

Integrating with the Community

A key pillar of Jai Vakeel's inclusion effort was community integration. Sabnani's interactions with families of the children at Jai Vakeel helped the team realize that many of the families had withdrawn from engaging in common social activities which others took for granted, such as going out to the movies, market places and other public gatherings.

To fill this void, Jai Vakeel introduced a focused and structured system for community integration aligned with the broader goal of inclusion within the family, society and community. The new program had two objectives: allow children with ID to interact with others in society and sensitize the community to the condition of ID. A central element of this program was 'field trips.' Jai Vakeel took its students on about 30 trips to cafes, malls, zoos, festivals and supermarkets. Parents were also encouraged to take their children out for a movie over the holidays and share their experiences. These trips helped children interact with others in the community, adapt to the world outside Jai Vakeel's campus and understand the norms of social interaction. They also sensitized the general population to the condition of ID thus helping mitigate the stigma surrounding it. Finally, they empowered and educated the parents and families to live a life that was as normal as possible under the circumstances. "Parents used to leave the responsibility of the child to Jai Vakeel. After 2013, we moved to a framework where the parent became a partner in this initiative. We could only give one to three sessions of therapy a week, but for the child to truly benefit, therapy needs to be every day. We wanted the parents to be partners," explained Rachna Dhingra, head of the healthcare and the rehabilitation center program.

The long-term strategy for community integration led to the formation of a placement team in September 2014. Chandra's team decided to approach partner companies to provide employment opportunities to capable students. The difficulty, however, lay in convincing potential employers to take on the responsibility of engaging a child with ID in their work environment. Companies were not just concerned about the well-being of the child, but also sensitizing other employees in the workplace to this condition.

Chandra also faced opposition from parents and families who did not want their children to leave Jai Vakeel's sheltered environment. Her team went to great lengths to understand and address the concerns of the families; they even had therapists shadow children as they travelled by public transport just to ensure that they were safe and capable of handling day-to-day tasks. But as more children started completing their education and getting employed, earning monthly salaries between Rs. 5,000 and Rs. 11,000 ($70 to $150), families began to see the benefit of Jai Vakeel training their children to become independent. Also, the belief that a child with ID would be a great financial burden on the family slowly started to fade.

Partnering with the Government

In an attempt to significantly increase its reach, Jai Vakeel collaborated with the government to sensitize more people. For 55 years, Jai Vakeel had been closely associated with the Government of Maharashtra and had been receiving a grant (nearly 40% of their total budget) to run their special schools. In 2010, under the leadership of Dr. Hegde, Jai Vakeel set up pediatric neurological medical camps in collaboration with other NGOs in rural Maharashtra. Doctors and medical professionals

provided free diagnosis, medical care, therapeutic intervention and counselled families with children with neurological issues. At these camps (at Nanded and Dhule) approximately 20,000 consultations were done, over a nine-year period. Jai Vakeel identified on the ground-partners who continued to support the child and the family after their initial diagnostic intervention. Seeing the success of these camps, the Government invited Jai Vakeel to be a part of their rural medical camps and help in sensitizing and training. Jai Vakeel's team spoke to over 8,000 *anganwadi*[e] workers in rural regions, educating them about the cause of ID. These workers, in turn spread awareness and helped sensitize a larger number of families across rural Maharashtra.

The government established the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities appointed state nodal agency centers to conduct activities to ensure equal opportunities and basic human rights to persons with disabilities. In 2017, Jai Vakeel was appointed a state nodal agency center (SNAC)[f] again. (Jai Vakeel had been a SNAC from 2004-2011 and in its first year won the award for the Best State Nodal Agency Centre.) As a SNAC, they conducted awareness workshops for over 5,000 stakeholders and formed local level committees in six districts of Maharashtra to provide guardianship for persons with autism, cerebral palsy and multiple disabilities.[12]

Measuring Impact

The leadership team recognized that it was critical to measure the impact of all their new initiatives. Measuring efficacy and outcomes would help put the institute 'on the map' to gain more support and funding. It was an uphill battle to get their name and purpose recognized. Difficulties arose when trying to quantify or communicate the true impact of their work. For students with mild or borderline ID, completing their grade 10 education was no doubt a success, but for those with severe or profound ID and multiple disorders, smaller steps had a tremendous impact.

"Impact is a tough story to tell," Dhingra affirmed, recalling the story of Ishwari, who was born with severe ID and Cerebral Palsy. "When Ishwari enrolled at Jai Vakeel, she was unable to sit up and lift her head. Indifferent to outside stimuli, she was quite isolated. Ishwari's mother devoted most of her time to caring for her and assisting her with simple activities. In addition to intensive medical care and therapy, we provided her with a special chair that would allow her to sit up and be more stable. This freed up a lot of time for her mother to complete other household activities. She became more social and had a smile that lit up her face."

Jai Vakeel was also a place where families found support and relief. As powerful as the impact was, it was not easy to quantify these effects and communicate them to companies and individuals outside.

The Next Steps: Mission 2022

By 2018, six years after Chandra took over and reworked the strategy with her team, Jai Vakeel's highly skilled team was providing numerous services to nearly 800 individuals annually and had placed 27 students in open employment. Some believed it was the dedication and autonomy within the organization that motivated them to work passionately and deliver results. Others said they were driven by the goal of simply making a difference to the lives of these children. In addition, Jai Vakeel

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[e] *Anganwadi*s were started by the Indian government in 1975 to combat child hunger and malnutrition in lower income families. Mothers with young children below the age of six came to these centers.

[f] A SNAC was an institutional arrangement of support the National Trust's activities. One SNAC in every state was appointed from amongst the reputed and well-established NGOs registered with the trust.

served roughly 2000 students through their two rural camps every year, one each in a district. These were medical camps undertaken with some 25 Jai Vakeel professionals. After the diagnoses and immediate provision of medicines, all follow-on services were directed through the network of other providers on the ground. This network was patchy and depended on the resources in the particular district.

Having achieved many of the goals outlined in 2013, Chandra's team set some ambitious targets for the students, families and foundation in Mission 2022. These included using the Jai Vakeel model to impact 10,000 more children and helping 50 more students be placed in open employment. They also aimed to use their database to develop inclusion parameters for children with ID, build a more employment-focused curriculum and make the sheltered workshop self-sustainable. To support these objectives, they sought to increase retail funding so that it accounted for a third of the total funds. Retail funding had the added attraction of being able to be deployed for capacity building and other such non-programmatic activities so crucial for the success of the organization.

Back in her office, Chandra reflected on all the tough decisions she had made and how difficult it had been to implement them. She derived strength from the knowledge that she was doing the right thing for the foundation. She had created the capacity to reach many more children in need. Chandra looked at the document with the goals they had set for themselves in Mission 2022, she thought about the many million children living with ID across the country, her mind went back to the Harvard Business School, where several lectures had emphasized, 'If you want to make real change, think out-of-the box.' She asked herself, "Do we have a scaling strategy? Is it likely to move the needle? If not, what else should we do?"

Exhibit 1A   The Four Pillars of Jai Vakeel

HEALTHCARE

Healthcare was the nerve center of the foundation; it was the first place where every new student was diagnosed and given individual therapy. Children with ID needed help with adaptive skills to live, learn, work and play. It was crucial to have the right interventions to help build skills such as communication, movement, and social behavior. Pediatricians, psychologists, occupational therapists, physiotherapists, speech therapists and social workers provided a host of healthcare services to all children for free or at a highly subsidized cost.

Diagnosis: A comprehensive medical, psychological and socio-economic assessment was done for every child for early detection, diagnosis, treatment and therapeutic intervention. Early intervention and accurate diagnosis led to significant improvements in students' cognitive, academic and social outcomes and prevented further complications.

Therapy: Different forms of need-based therapy were used to improve students' communication, behavior and motor functions.

Counseling and Guidance: Jai Vakeel also ensured parents were counseled and trained with the goal of improving the quality of their personal lives as well as to equipping them to better manage their children. The Jai Vakeel staff wanted to ensure that parents were dedicated to their child's journey.

Pediatric Neurology Camps in Rural Maharashtra: Jai Vakeel conducted bi-annual camps in Maharashtra to diagnose and provide medical and therapeutic interventions along with nutritional supplements for neurological disorders and epilepsy. Teams of 20-25 professionals engaged in these camps, which had over the past 10 years served some 18,000 children.

EDUCATION

The Jai Vakeel Foundation started its first special school in 1944. It had 2 other branches, with around 40 students each at Deolali and Talegaon. The curriculum covered the entire spectrum of ID: for children with mild to moderate ID, the focus was more on functional academics whereas for children with severe to profound ID, the focus was on activities of daily living.

Through the National Institute of Open School (NIOS) program, Jai Vakeel aimed to provide mild and borderline ID students formal education to prepare for the Grade 10 Secondary School Certificate examination. NIOS levels A, B and C were equivalent to grades III, V and VIII. In 2019, 4 students enrolled in the SSC examination and successfully completed 4 out of 5 papers.

The students also participated in extracurricular activities such as dance, sports, yoga and gardening to help with overall development. Over the years, Jai Vakeel students also participated at the International Special Olympics; many of whom won gold medals at these events.

At the age of 17, based on their aptitude and ability, students were trained and placed. A number of options were available to them such as vocational training, open employment, self-employment, sheltered employment, home based rehabilitation and respite care program.

SKILL DEVELOPMENT

The vocational training center and sheltered workshop were started in 1948 to encourage self-reliance in young adults with ID. Students, aged 18 to 21 years were trained in different vocational activities to improve motor coordination and capacity to work, build their self-confidence and become familiar with the concept of earning.

At the age of 21 the individual qualified for open employment or the sheltered employment depending on their capacity. The students in the sheltered workshop continued to be employed till the age of 50. Selling the

products made in the workshop helped create awareness about ID and showcase the talents and abilities of the students.

SUPPORT SERVICES

Respite Care was created in 2014 for severe and profoundly challenged young adults with ID between the ages of 18 and 25 years. The focus was on teaching them to become independent and being able to manage activities of daily living. Students were engaged in recreational and light physical activities to maintain their physical and mental wellbeing. This not only benefitted the students but provided respite to their parents or primary caregivers. There were 53 such individuals in Respite Care as of 2018.

Source: Company documents

Exhibit 1B   The Four Pillars of Jai Vakeel

A Physical Therapy Session

Education Classroom

Skill Development Workshop

Source: Company documents

Exhibit 2   Healthcare, Education, Skill Development: Highlights and Partnerships

	Healthcare	**Education**	**Skill Development**
Highlights	*Diagnosis:* •150 + students diagnosed annually *Therapy:* •4500+ free therapy sessions provided annually •64% therapy sessions had Parents present learning from the Therapist •81% of the Therapy Goals were met or partially met Training workshops: •40+ workshops for all stakeholders annually Technology: •Customized Information Management System (MIS) used to monitor all Healthcare services offered	•350 students at the main campus and another 100 students in three satellite centers. Ages 3 to 18. Curriculum – 23% increase in learning levels •NIOS – 4 students scored an average of 74% in their 10th Grade English: 74% Baking: 71% Data Entry: 67.5% Painting: 62% •Digital Literacy – Introduced I-Pad to aid learning - 45% average improvement •Sports achievements – 130 medals •Animal Assisted Therapy – 34% average improvement	•200 students in vocational training and sheltered workshop. Ages 18-21. Product Sales – 16% CAGR in sales in the last 6 years Last year sales growth was 63% •Products – new range of Art based products introduced •29 students placed in Open Employment in the last 4 years
Partnerships	•Animal Angels Foundation - to provide Animal Assisted therapy to students with Autism •Perkins International - to provide Visual Rehabilitation to students with Visual impairment •Metropolis – subsidized health check for our students Ummeed - Trainings for Parents and staff	•Teach India – spoken English for Teachers •Advaika - counselling for parents •Toy Bank – Play therapy •Victory Arts Foundation – Dance training	•L'Occitaine Spa and Cipla Foundation – customized products •La Monnaie – Training and Open Placement for students

Source: Company documents

Exhibit 3A Jai Vakeel's Income and Expenditure

Income	2017 (INR)	2018 (INR)	2017 (USD)	2018 (USD)
Interest (Accrued and realized)	1,14,73,106	1,28,50,233	170,985	183,575
Government Grants Scholarships	4,18,43,496	4,49,68,086	623,599	642,401
Donations received	4,67,22,014	5,21,24,788	696,304	744,640
Other Receipts (Sale of Vocational Training Products; Miscellaneous Income and other contributions)	1,14,59,266	71,67,449	170,779	102,392
Total income	11,14,97,882	11,71,10,556	1,661,667	1,673,008

Expenditure				
Direct	**8,11,05,515**	**9,02,65,523**	**1,208,726**	**1,289,507**
Purchases	12,72,036	27,93,473	18,957	39,907
Staff Expenses	6,14,82,361	6,62,11,620	916,280	945,880
Student Expenses	1,25,77,033	1,57,51,865	187,437	225,027
Overheads	48,04,127	45,26,693	71,597	64,667
Support services	9,69,958	9,81,872	14,455	14,027
Indirect	**1,19,47,599**	**1,34,59,122**	**178,057**	**192,273**
Total Expenditure	**9,30,53,114**	**10,37,24,645**	**1,386,783**	**1,481,781**
Surplus of Income Over Expenditure				
Carried Over to Balance Sheet	**1,84,44,768**	**1,33,85,881**	**274,885**	**191,227**

Note: The exchange rate for 2017 is based on the historical average yearly exchange rate published by the Reserve Bank of India.

Source: Company documents

Exhibit 3B   Jai Vakeel's Financial History

	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17	2017-18
Corpus (INR)	3,27,42,255	6,55,69,564	6,57,86,064	7,61,28,564	11,16,81,344	13,17,71,604	14,33,21,538
Corpus (USD)	683,240	1,205,323	1,087,373	1,245,967	1,705,059	1,963,809	2,047,450
Expenditure (INR)	5,23,75,288	6,30,14,953	6,89,59,049	7,26,60,035	7,85,91,688	9,30,53,114	10,37,24,645
Expenditure (USD)	1,092,907	1,158,152	1,139,783	1,188,351	1,200,450	1,387,362	1,481,781
Average Exchange Rate	47.9	54.4	60.5	61.1	65.5	67.1	70.0

Note: The exchange rates are based on the historical average yearly exchange rate published by the Reserve Bank of India.

Source: Company documents

Exhibit 4   Jai Vakeel's Funding Sources

	2009-10	2013-14	2017-18
Government Grant	64%	66%	41%
Trust	21%	15%	27%
Corporate	3%	5%	21%
Individual	12%	14%	11%

Source: Company documents

Exhibit 5   Board Members of Jai Vakeel, 2007 and 2018

Board Members 2007	Board Members 2018
Zia Cama – Joint Director Rural Branch (A member of the founder's family)	Zia Cama – Joint Director Rural Branch (A member of the founder's family)
Pesi Shroff (A member of the founder's family)	Pesi Shroff (A member of the founder's family)
J.D. Sumariwalla – Legal Advisor	Kekoo Colah (A member of the founder's family)
Dr. Jay Shastri – Director of Rural Branch	Dr. Anahita Pandole – President
Yasmin Irani	Rajendra Kasliwal – Treasurer
	Vedika Bhandarkar – Joint Treasurer
	Dr. Anaita Hegde – Medical Director
	Archana Chandra – CEO of Jai Vakeel
	Meghana Vipradas – Secretary
	Nari Mehta
	J.D. Sumariwalla – Legal Advisor
	Yasmin Irani
	Jay Shastri – Directory, Rural Branch

Source: Company documents

Exhibit 6   Jai Vakeel Partnerships

Jai Vakeel wound down its laboratory and tied up with **Metropolis**, a chain of diagnostic centers providing quality healthcare services. This partnership not only improved the quality of medical services, but also allowed for faster and more efficient diagnoses.

For the visually impaired students, Jai Vakeel partnered with **Perkins School for the Blind**, which helped provide underserved children and young adults with visual impairment high-quality education that enriched their lives. Perkins School for the Blind worked with students of Jai Vakeel who had multiple disabilities and visual impairment. It conducted an entire program and funded the professionals needed for therapy.

The Jai Vakeel staff, therapists and leadership team attended trainings by **UMMEED**, an organization offering training programs for educators of children with special needs. They also invited speakers from UMMEED to their internal trainings.

For students with autism spectrum disorder, Jai Vakeel partnered with **Animal Angels Foundation** to provide animal (dog) assisted therapy. The pilot program showed great results and by 2019, it had become a permanent feature of Jai Vakeel's Autism Centre. The Animal Angels team managed the entire program, conducted the therapy sessions and monitored student progress.

Jai Vakeel partnered with **L'Occitane**, a high-end spa, to increase the reach of the products made by the skill development center. This helped them reach a larger audience and increase the sales of products like incense, candles and bags.

To improve the scale of skill development training, Jai Vakeel partnered with **La Monnaie**, a social enterprise working with people with disabilities to provide skills and job opportunities. La Monnaie conducted a certified skill development program that trained students in housekeeping and helped them become fit for open employment. The training also focused on building soft skills like interpersonal communication, confidence and work ethics. They supported the students and their parents through the entire 2-month program.

At the end of the program, 8 students qualified for open placement; they were placed in the housekeeping department of Integrated Facility Services at the Garware Club. La Monnaie continued to track and support them for a year after their placement. Since the Jai Vakeel placement team usually worked with one student at a time, this partnership provided an established curriculum covering all aspects of the training and final placements but also allowed them to scale - placing 8 students in one go.
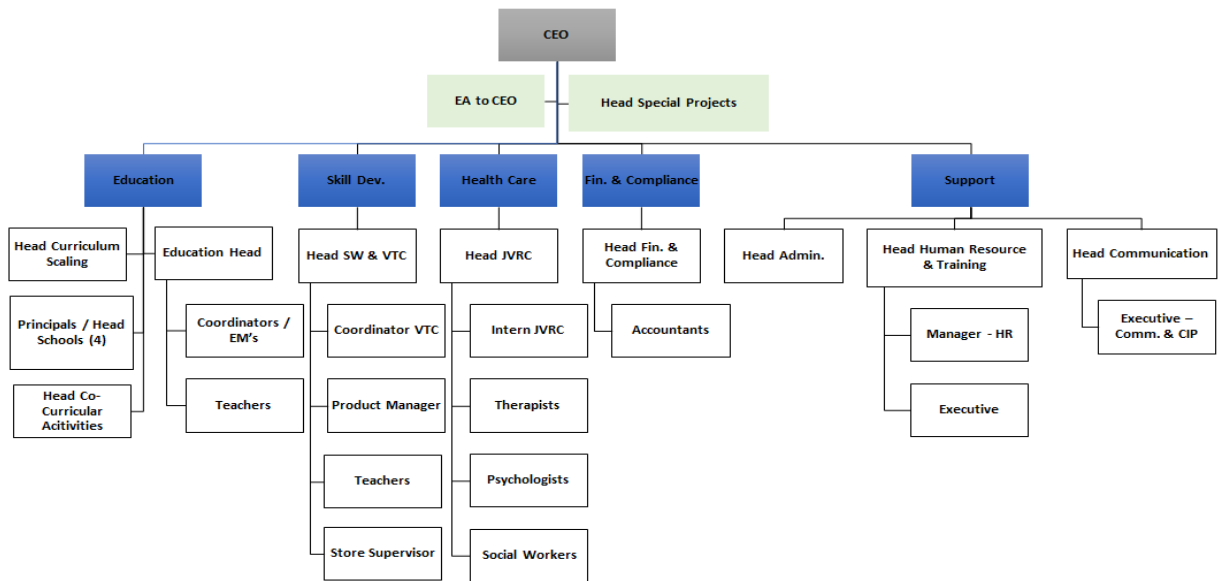
Source: Company documents

Exhibit 7A   The Old Organization Structure

Source: Company documents

Exhibit 7B   The New Organization Structure

Source: Company documents

Exhibit 8   Excerpts of Data collected in Oyster

				Therapy sessions			
	Students	Sessions	Absenteeism (%)	Outcome			Parents Present (%)
				Exceeded/Met	Partially Met	Not Met	
OTPT	119	2295	7	19.5	76.1	4.4	70
Speech	87	1314	25	7.9	87.5	4.6	59
Psychology	50	967	17	15.02	78.4	6.3	62
Total	182	4576	14	15.08	79.4	4.9	65

Note: OTPT refers to occupational and physical therapy; it involves improving activities of daily living and controlling the movements of the human body

Source: Company documents

[1] Jai Vakeel Foundation and Research Centre, 2018 Annual Report (Mumbai: Jai Vakeel, 2019) p.6.

[2] Jai Vakeel Foundation and Research Centre, 2018 Annual Report (Mumbai: Jai Vakeel, 2019) p.7.

[3] Dasra and Bank of America, *Count Me In – Building an inclusive ecosystem for persons with intellectual and developmental disabilities*, March 2019, https://www.dasra.org/assets/uploads/resources/Final%20IDD%20Report%20-%206th%20March.pdf, accessed 20th April 2019.

[4] Dasra and Bank of America, *Count Me In – Building an inclusive ecosystem for persons with intellectual and developmental disabilities*, March 2019, https://www.dasra.org/assets/uploads/resources/Final%20IDD%20Report%20-%206th%20March.pdf, accessed 20th April 2019.

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[9] Company Documents, Jai Vakeel Foundation, June 2019.

[10] Company Documents, Jai Vakeel Foundation, June 2019.

[11] Jai Vakeel Foundation and Research Centre, 2018 (Mumbai: Jai Vakeel, 2019).

[12] The National Trust, Government of India, http://thenationaltrust.gov.in/content/innerpage/local-level-committee-llc.php, accessed on 15th June 2019.