

THE SERRENDIP

A FOUNDATION OF FINDINGS AND APPLICATIONS
FOR PERSONS WITH AUTISM AND RELATED DISORDERS

ANNUAL REPORT 2018-19



The Serrendip



WWW.SERRENDIPFORAUTISM.COM

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FOR PERSONS WITH AUTISM AND RELATED DISORDERS

Address by the President



I am truly pleased to communicate that The Serrendip is coming out with its first annual report.

It is a small beginning for all of us who have decided together to impact the life of persons with Autism positively with time; I am sure The Serrendip will emerge as a **go to place** for the needy.

In my experience, at a personal level, I feel that the persons with Autism have enormous unexplored talent. These talents need to be identified early in life and if given the right training at the right time, the individuals with Autism can stand out.

The year which has gone by, had a series of activities such as distribution of posters on **Red Flag Indicators of Autism** in various organizations of Jabalpur District, a survey on finding the number of kids with Autism in 60 mainstream schools of Jabalpur, formal launch of The Serrendip in the city of Jabalpur, launch of a calendar 2019, created with the help of sketches of Ganesha done by a young adult with Autism-Ujjwal Sharma.

The Serrendip intends to initiate ground level work from the year 2019 and have planned series of activities. The impact over will be the creation of a registry of people with Autism across India, enhancing awareness at all levels, strengthening the inclusive education, exploring employment opportunities and related training models.

I wish to thank all office bearers, well wishers and families who have sailed along with us and help us achieve our goals.

Warmly

Navin Sharma

AWARENESS

World Autism Awareness Day- April 2, WAAD 2018 A Report-

April 2018, called for the awareness programme on Autism where posters on the Red Flag Indicators of Autism were distributed in and around Jabalpur City in relevant places like clinics, special schools and some hospitals. Collector Mrs. Chhavi Bharadwaj was also made aware about Autism. A few posters were given to an organisation in Singarouli. Filers on Autism were distributed through paper circulation in different parts of Jabalpur city.



ACHIEVEMENTS

Kavita Sharma received one National Level Award- "MOTHER THERESA AWARD"

दिव्यांगों की सेवा का प्रसाद मिला राष्ट्रीय स्तर का सम्मान - बेस्ट पेरेंट कटेगरी का " एवार्ड " 28 अगस्त 2018, स्कॉडा बिजनेस सेंटर, सोन भवन, पटना, बिहार में आयोजित राष्ट्रीय स्तर के सम्मान समारोह "18वें बिहार सम्मान समारोह " में विकलांगता व अन्य सामाजिक कार्यों के क्षेत्र में श्रीमती कविता शर्मा के प्रयोगों व प्रयासों के कारण उन्हें सर्वश्रेष्ठ पेरेंट कटेगरी का " मदर टेरेसा एवार्ड" प्रदान कर गौरवान्वित किया गया । कार्यक्रम के मुख्य अतिथि बिहार के पूर्व मुख्य मंत्री माननीय जीतन राम मांझी बिहार के राज्य निःशक्तजन आयुक्त (डिसेबिलिटी कमिश्नर) माननीय श्री शिवाजी कुमार ने प्रतीक चिन्ह व सम्मान पत्र देने के बाद जब सार्थक विचारों का उद्घोषण किया तो लगा मानो पूरी डिसेबिलिटी की फील्ड सम्मानित हो रही थी ।

कार्यक्रम में देश भर के राज्यों से आये विकलांगता के क्षेत्र में कार्य करने वाले विशेषज्ञों, समाज सेवियों, अंतरराष्ट्रीय स्तर के दिव्यांग खिलाड़ियों और उनके कोचों को सम्मानित किया गया ।



AWARENESS



Dr. Desh Keerti Menon is the former director of the National Institute for Empowerment of Persons with Intellectual Disability, PO Manovikas Nagar, Hyderabad, Telangana. He is one of the Technical Advisory Board Member of The Serrendip. He has raised many questions through his article, it is time that the parents and professionals work on the suggested areas.

SOME THOUGHTS ON THE ADULT LIFE OF PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD) IN INDIA

**Dr. Desh Keerti Menon, Dr. Jayanthi Narayan, and
Dr. A T Thresiakutty**

Formerly from the National Institute for
Empowerment of Persons with Intellectual Disability,
PO Manovikas Nagar, Hyderabad 500 009,
Telangana, India

The figure of adults with Intellectual and Developmental Disabilities (IDD) living with their families in India is not known. It is a question that needs to be answered. Adults with IDD living in shelter homes, forensic facilities under the justice juvenile homes, jails, mental hospitals, on the streets, supported living constitute about 5% of the population of adults with IDD. It is therefore guess work to assume that about 95% adults with IDD live in family homes supported by parents, siblings, grandparents, and relatives. What kind of social and economic issues they face have been documented in few family studies carried out in India. There is definitely a need for carrying out a comprehensive epidemiological study in India to answer these questions. Concomitants of adult life are illustrated in this paper.

ISOLATION:

Most adults have little or no opportunity of social interaction with their peers or interest groups. Their own siblings get married and move away. Parents in their old age are able to fulfill minimum basic needs, but social, leisure, and recreational needs are rarely met. There are a few incidents of suicide committed by adults with IDD. Whether it is due to social isolation or underlying depression needs to be studied further.

Where ever parents have organized themselves into a group, they have been able to provide wide variety of services like, vocational training, group employment, day activities, leisure and recreational programs.

SEX AND RELATIONSHIPS:

Most adults with IDD are deprived. Adult males profess their love and fondness for their favorite heroine from the cinema world. In adult male hostel or sheltered home facilities, there are instances of open masturbation, and sexual assaults. Adult females are restrained from expressing their sexuality. Women with IDD living in shelter homes run greater risk of sexual exploitation. There is a need for training adults with IDD on privacy and consenting sexual relationship. What percentage of men and women with IDD has experienced unwanted sexual experience? It has never been documented. It is time to gather some data.

A CHILD WHO HAS NEVER GROWN UP:

Most adults when interviewed consider themselves as a child, with a few exceptions. Parents and professionals alike address them as children and treat them as a child. However, there are few instances where adults with IDD project themselves like any other adult in their community. There is a case of a person who had been recently appointed as a Peon in Judicial Courts. He traveled long distance alone by taking overnight Bus to attend a meeting on a Sunday. After the meeting he went back to attend his job on Monday.

AWARENESS

Being a person with a Down's syndrome, he was able to fend off unwanted attention with respect and dignity. There was another instance of a person who could ride a motor cycle within the city and travel intercity as well. He did not have a Driver's license. When stopped by the Police, he was let off when they realized that he is a person with IDD. It is time that persons with IDD should get a Driver's license, drive motor vehicles legally and become a shining example. These are few examples of persons with IDD fully independent with adult behaviors, like landing a government job, travelling and spending personally earned money without any body's supervision, riding a motor bike, managing law officers without any support from anyone.

ADULT EDUCATION:

Adult education programs located in neighborhood colleges are currently non-existent in India. Most adult education programs are available in extended School setting. Could that be the reason that persons with IDD never fully transition into adult roles?

EMPLOYMENT:

A person with IDD who lands a job in the open market does so because of the goodwill of the employer. Very rarely a person gets employed on his or her own merit on competitive basis. Most people who are employed in any form of setting continue to live with the family. Without the support of the family, homelessness is staring at them.

INDEPENDENT LIVING:

The National Institute for empowerment of persons with Intellectual Disability had supported a serial that was telecast on Doordarshan titled "Ek Ghar Aas Paas" in late 1990s. That theme of neighborhood residence is still relevant today as it was 20 years ago. Many people with IDD aspire to live on their own, independently. However, parents and family members are reluctant for fear of exploitation. There are many successful experiments on group living where even women with IDD go out shopping in the neighborhood on their own. The feedback from an experiment at Swyamkrushi, Hyderabad shows that shopkeepers in the neighborhood become familiar and encourage integration.

GETTING LOST:

Freak accidents do happen regularly. If a person with IDD gets lost, the chances are slim for reuniting with the family. There are few success stories. These incidents are preventable. Data base of Aadhar card can be the best bet to reunite families.

SELF ADVOCACY:

In most self advocacy programs in India, persons with IDD speak what their trainers want them to speak. Persons with IDD are capable of taking charge of their lives. There are courses for persons with IDD on self management in decision making, financial autonomy, relationships, understanding social situations, assertiveness, and keeping safe in the community. Unfortunately, most caregivers and family carers in India do not give people with IDD adequate opportunity to become completely independent out of fear that they may get lost or be exploited in the community. Many parents are reluctant to give up the caring role although the person they are caring for is capable of independent functioning.

PERSONS WITH IDD AS CARERS:

There are many examples of persons with IDD working as Care assistants, but none as fully fledged Carer. Many persons with IDD work as Classroom assistants, Shop assistants, Office assistants, or under supervision in wide variety of situations. It is time to explore if persons with IDD can take up responsibility as Carers. Many mothers with IDD take good care of their children, with training on mothering skills. It is time to try out a skill training program as a part of National Vocational Curriculum.

TRAINING AS MOTHERS: Mothers with IDD living in a large family find support in child rearing. Those living in small families may not be able to cope with pregnancy, antenatal care, child rearing, child development, health and nutrition issue related to babies without external support. There is a need for developing support and training programs for such Mothers with IDD.

AWARENESS

UNDERSTANDING DEATH:

Persons with IDD find it hard to understand death of a person to whom they were close. There is an instance of a person with IDD when told about life after death, she had put a tape around all windows, and tap openings were sealed. She thought the spirits will come back to haunt her. People with IDD grieve in their own way. One has to find ways to help and support them.

DEMENTIA:

Persons with Down's syndrome (DS) have greater risk of developing Alzheimer's disease called old age Dementia as they get older quickly. A mother in Delhi wished her adult son with DS to pass away before she did. Her worry was mainly who would look after the aging person with a DS. There is hardly any person with DS in India beyond the age of 55 years, while longevity in Western countries is much higher. There is a need for screening Dementia from age 30 onwards so as to detect it early and prepare family and paid Carers on how to look after a person with DS having Dementia in early stage, middle stage and late stage. The duration between detection and eventual death is about 8 years in persons with DS. Prevalence of Dementia also increases with age, in the age group 61 to 70 years; the prevalence is nearly 60%.

OLD AGE:

There are other old age issues, prevalence of heart disease, prostate in men, menopausal issues that bring hormonal changes in women, Osteoporosis, falls that lead to injuries and breaking of bones. Persons with IDD find it hard to cope with the changes, therefore become confused, depressed, irritable or anxious.

PARENTS HEALTH:

Family studies have documented impact on parents and siblings. Few studies have linked psychological stress and adverse mental health outcomes of having a person with IDD in the family. But there are no studies on the morbidity and mortality amongst parents of those with IDD as compared to general population. This idea stems from an observation made in a study that required one year follow up interview in a cohort of 15 parents in a suburb of Kolkata. Two parents had died during the follow up period. This seems a very high

proportion. Does long term caring takes a toll on the health of the Caregiver? This needs to be investigated. In summary, India is progressing very rapidly. The economic benefits should reach all sections of the community. It is the joint effort of professionals, family members, and the persons with IDD themselves to develop programs and systems that can fulfill the needs of persons with IDD at all stages of their life.

ACKNOWLEDGEMENTS:

The authors would like to thank Prof. Thomas Kishore of NIMHANS, Bangalore and Prof. Ram Lakhan of Berea College, Kentucky, USA for their editorial comments and suggestions.



THE LAUNCH



'द सर्रेडिप' संस्था जो स्वलीनता (ऑटिज़्म) से ग्रसित व्यक्तियों के लिए प्रयोगों एवं अनुप्रयोगों पर आधारित और कार्यरत है, का शुभारम्भ जबलपुर में एक गैर सरकारी (NGO) के रूप में दिनांक 17.11.2018 को होटल सत्य अशोक, जबलपुर, मध्यप्रदेश में हुआ। कार्यक्रम के मुख्य अतिथियों के रूप में सुप्रसिद्ध स्त्री रोग विशेषज्ञ- डॉ अमिता सक्सेना, डॉ डी.के. मेनन- वरिष्ठ वैज्ञानिक अमेरिका, डॉ सुधीर मिश्रा, एम्. डी. और सीईओ ब्रह्मोस मिसाइल, डॉ नियोगी- डेप्युटी जनरल मैनेजर शेल्बी अस्पताल, डॉ धीरेन्द्र खरे- डायरेक्टर अनुसंधान जवरहरलाल नेहरू कृषि विश्वविद्यालय सम्मिलित हुए। अनेक अभिभावक, मित्र गण और परिवार के सदस्य भी इस कार्यक्रम में सम्मिलित हुए। संस्था के अध्यक्ष डॉ नवीन कुमार शर्मा ने अतिथियों के स्वागत करने के बाद द सर्रेडिप के उद्देश्य एवं लक्ष्य के बारे में बताया और इसकी कार्यशैली पर प्रकाश डाला | इस अवसर पर श्रीमती कविता शर्मा, संस्था की सचिव ने संस्था की प्रमुखता एवं कार्य शैली पर प्रकाश डाला | डॉ अमिता सक्सेना ने वेबसाइट का उद्घाटन किया। डॉ मेनन ने अपने भाषण में अनेक सुझाव दिए कि ऐसे व्यक्तियों का समाज में कैसे समावेश किया जा सकता है | उन्होंने अपने व्यक्तिगत विचार और उदाहरण दिए | सभी मुख्य अतिथियों ने भिन्न भिन्न विषयों पर अपने विचार व्यक्त किये एवं समाधान का विवेचन किया | द सर्रेडिप ने इस अवसर पर एक कैलेंडर 2019 भी लांच किया जिसमें एक वयस्क, जो आटिज़्म से प्रभावित है , के द्वारा बनाये हुए गणेश जी के चित्रों को सम्मिलित किया गया |



PARTICIPATION AND COLLABORATION

Global Autism Convention 2018, Bangalore

Global Autism Convention 2018 (GAC 2018) was held at St. John's National Academy of Health Sciences Auditorium, Bangalore from December 10 - 12, 2018. Kavita Sharma, secretary of The Serrendip was invited to interact with the delegates through a panel discussion on Inclusion and Autism and create a highly empowered autism community across the globe.

Kavita Sharma also contributed an article on INTEREST INTEGRATED INTERVENTION for the souvenir which was released during the convention.

The Serrendip also distributed 300 calendars during this convention, these were created with the help of the sketches done by Ujjwal Sharma. He was also felicitated as an artist in MEET THE STARS event during the convention.



PARTICIPATION AND COLLABORATION

DPS Gandhinagar April 2018

Kavita Sharma, Secretary of The Serrendip was invited as a speaker by the DPS society of Gandhinagar to speak on the topic. "Smart Classrooms . The Need of the hour". This was to promote inclusive education of persons with disabilities (pwws). It was an International Convention on Inclusive Education- Bringing Change in the Class room. organised by Delhi Public School Society in April between 16-18, 2018.



PARTICIPATION AND CONTRIBUTION

Kavita Sharma- Advisory Board Member for Government of Kerala, Business Advisory Committee ASAP for the PwD sector

In July 2018. Kavita Sharma was contacted and later in October 2018 invited by the Government of Kerala (GOK), Business Advisory Committee for the PwD sector to become one of the Advisory Board Members. The first meeting was held on October 3rd, 2018 at Trivandrum. The discussion was around the topic of Skill Development for persons with disabilities and how their existing ASAP. Additional Skill Acquisition Programme can be extended and implemented to PwD sector.

It was culminated in to identifying three types of disabilities that the GOK wants to work for; Locomotor impairments, visual impairments and hearing impairment. GOK has already been working on skill development for the Hearing impaired persons in collaboration with NISH. National Institute for Speech and Hearing Impaired, Trivendrum. It is a welcome move from the State Government of Kerala



A SURVEY

A Survey in Jabalpur City to understand the Status of Inclusion of Individuals with Autism in Mainstream Schools

A survey on the incidences of Autism Spectrum Disorders was done in sixty (60) mainstream schools of the city of Jabalpur, MP during the months of July. September 2018. The District Education Officer of Jabalpur provided the permission to reach out to the schools in the city. Ms. Monika Tiwari was appointed as the coordinator for this project as a qualified professional. This survey result findings suggest the presence of 40 boys and 4 girls who have Autism of varied degrees in these 60 schools. The total population of students in these schools was 16895. These are the students who have been studying in mainstream. These schools were randomly picked and were a mix of aided/non aided government and private schools.

The second phase of the survey will focus on meeting the families of these kids and school authorities to understand the availability of desired facilities and help them enhance learning.



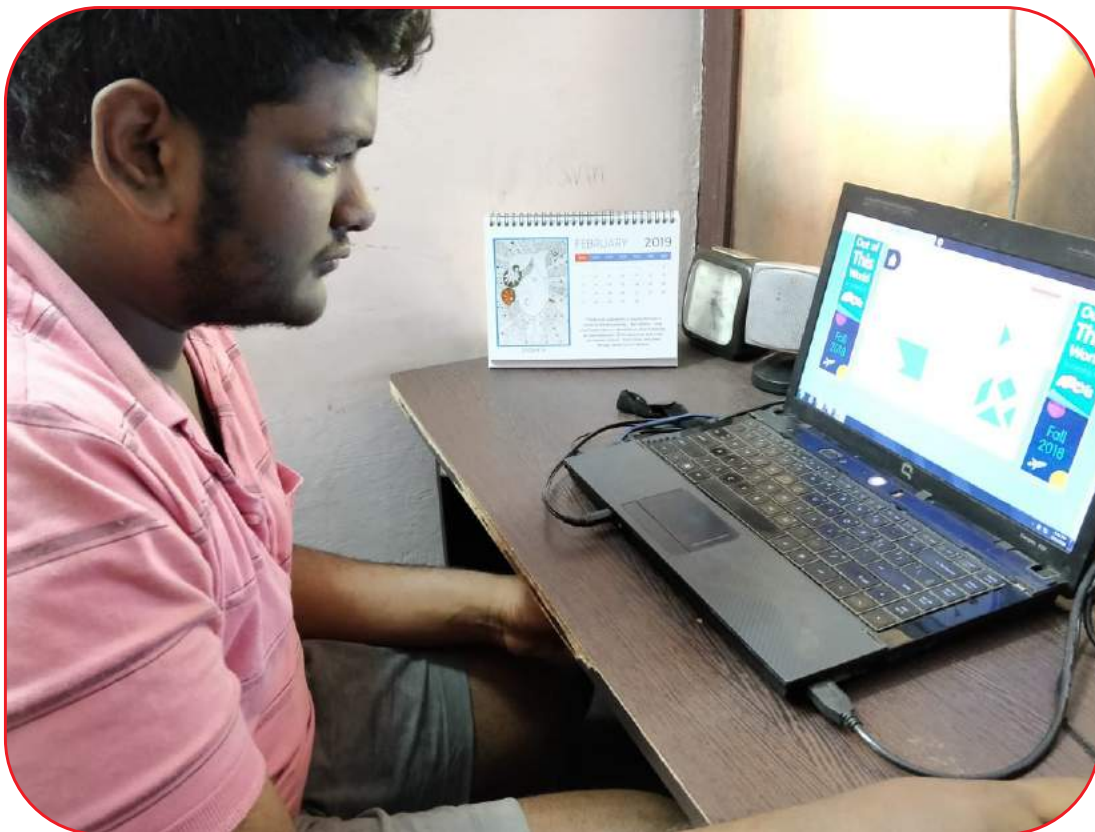
AWARENESS

AWARENESS

The Serrendip launched Calendar 2019 to continue to create the awareness of Autism in the society. These calendars were created with the help of the Ganesha Sketches done by Ujjwal Sharma, who is a 23 year old young man with Autism. He has completed a course on Graphic Designing, certified by NSDC, INDIA. 300 of these calendars were distributed in Global Autism Convention in Bangalore, some were sent through friends to various other organisations and people in Delhi, Gurugram, Kanpur, Tripura, Kolkata, Chennai, Trivendrum, Chhattisgarh, Kochi, Pudducherry, Dubai, Kenya and Belgium.

State Disability Commissioner, some doctors, educators and many many friends were made aware of the strengths of Autism through these calendars.

Lotus Foundation, Chennai



VOLUNTEERS AT WORK

LAUNCH PREPARATION OF THE SERRENDIP



AWARENESS

Awareness Activities through Calendar Distribution



AUDIT REPORT



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email : utatiya@yahoo.co.in

UTTAM TATIYA & CO.
— CHARTERED ACCOUNTANTS —

Uttam Chand Tatiya, B.Com, F.C.A.

AUDITOR'S REPORT

1. We have audited the Balance sheet of the THE SERRENDIP, 53, ALOK NAGAR, ADHARTAL, JABALPUR, SAMITI REGISTRATION NO – 04/14/01/19344/17, INCOME TAX 12AA REGISTRATION NO – 018-19/A/10207 DATED 26.11.2018 and also the annexed Income & Expenditure Account & Receipts & Payments Account for the Year ended 31st March 2019 and report that:- These financial statements are the responsibility of the management. Our responsibility is to express an opinion on these financial statements based on our audit.
2. We conducted our audit in accordance with auditing standards generally accepted in India. Those Standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. Some transactions not supported by external vouchers and are accepted based on entries in the books of accounts. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion. Balances are subject to confirmation of the parties. Audit has been conducted on the basis of available vouchers. Balances are subject to confirmation of the parties.
 - (1) We have obtained all the information and explanations which to the best of our knowledge and belief were necessary for the purposes of our audit.
 - (2) The Balance Sheet and the Income and Expenditure Account dealt with by the report are in agreement with the books of Accounts maintained and produced before us.
 - (3) In our opinion and to the best of our information and according to the explanations given to us, the Statements give a true and fair view :
 - (i) In the case of the Balance Sheet of the state of affairs as at 31st March 2019 and
 - (ii) In the case of the Income and Expenditure Account of the Surplus for the Year ended on that date.
 - (4) **Accounting Policies :**
 - a. Accounts are maintained on the basis of Mercantile system of accounting.
 - b. Fixed Assets are stated at cost. Depreciation provided for the year.

FOR UTTAM TATIYA & CO
CHARTERED ACCOUNTANTS



JABALPUR

DATED: 22.04.2019

UTTAM CHAND TATIYA
PROPRIETOR
MEMBERSHIP NO:-073597
FRN – 004633C

AUDIT REPORT

THE SERRENDIP

53, ALOK NAGAR, ADHARTAL, JABALPUR

SAMITI REGISTRATION NO - 04/14/01/19344/17

INCOME TAX 12AA REGISTRATION NO - 018-19/A/10207 DATED 26.11.2018

RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR 01.04.2018 - 31.03.2019

<u>RECEIPTS</u>	<u>AMOUNTS</u>	<u>PAYMENTS</u>	<u>AMOUNTS</u>
<u>Opening Balances :</u>		Brochure & Calendars	39,600.00
HDFC Bank A/c 17255	10,018.00	Coordinator Survey Expenses	20,000.00
Cash in Hand	1,524.00	Inuaguration Expenses	35,500.00
		Stationery & Printing	17,765.00
		Travelling Expenses	25,021.00
		Website Expenses	14,160.00
<u>Income:</u>		Advocate Fees	20,000.00
Bank Interest	323.00	Audit Fees	5,000.00
		Bank Charges	70.80
Donation from Members	217,372.00	Courier Expenses	6,731.00
		Expenses Sub Total	183,847.80
		<u>Closing Balance :</u>	
		HDFC Bank A/c 17255	42,546.20
		Cash in Hand	2,843.00
	<u>229,237.00</u>		<u>229,237.00</u>

PRESIDENT


SECRETARY

JABALPUR

DATED: 22.04.2019

AS PER OUR REPORT ATTACHED

FOR UTTAM TATIYA & CO
CHARTERED ACCOUNTANTS
FRN - 004633C


UTTAM CHAND TATIYA
PROPRIETOR
Membership No - 073597



AUDIT REPORT

THE SERRENDIP
53, ALOK NAGAR, ADHARTAL, JABALPUR
SAMITI REGISTRATION NO - 04/14/01/19344/17
INCOME TAX 12AA REGISTRATION NO - 018-19/A/10207 DATED 26.11.2018
INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR 01.04.2018 - 31.03.2019

<u>EXPENDITURE</u>	<u>AMOUNTS</u>	<u>INCOME</u>	<u>AMOUNTS</u>
Brochure & Calendars	39,600.00	Bank Interest	323.00
Coordinator Survey Expenses	20,000.00		
Inuaguration Expenses	35,500.00	Donation from Members	217,372.00
Stationery & Printing	17,765.00		
Travelling Expenses	25,021.00		
Website Expenses	14,160.00		
Advocate Fees	20,000.00		
Audit Fees	5,000.00		
Bank Charges	70.80		
Courier Expenses	6,731.00		
Depreciation	9,728.00		
SURPLUS	24,119.20		
	<u>217,695.00</u>		<u>217,695.00</u>

BALANCE SHEET AS ON 31.03.2019

<u>LIABILITIES</u>	<u>AMOUNTS</u>	<u>ASSETS</u>	<u>AMOUNTS</u>
<u>Genral Fund :</u>		<u>FIXED ASSETS :</u>	
Opening Balance	35,862.00	Schedule 'A'	14,592.00
Add: Surplus for the	<u>24,119.20</u>		
	59,981.20	<u>Cash and Bank Balances</u>	
		Cash in Hand	2,843.00
		<u>Cash at Bank</u>	
		HDFC Bank A/c 17255	42,546.20
	<u>59,981.20</u>		<u>59,981.20</u>

PRESIDENT

SECRETARY

JABALPUR

DATED: 22.04.2019

AS PER OUR REPORT ATTACHED
 FOR UTTAM TATIYA & CO
 CHARTERED ACCOUNTANTS
 FRN - 004633C

UTTAM CHAND TATIYA
 PROPRIETOR
 Membership No - 073597



AUDIT REPORT

THE SERRENDIP
53, ALOK NAGAR, ADHARTAL, JABALPUR
SAMITI REGISTRATION NO - 04/14/01/19344/17
INCOME TAX 12AA REGISTRATION NO - 018-19/A/10207 DATED 26.11.2018

FIXED ASSETS

SCHEDULE "A"

<u>PARTICULARS</u>	<u>W D V AS ON</u> <u>01.04.2018</u>	<u>Rate</u> <u>(in %)</u>	<u>Depreciation</u>	<u>W D V AS ON</u> <u>31.03.2019</u>
Computer & Printers	5,700.00	40%	2,280.00	3,420.00
Website Development	18,620.00	40%	7,448.00	11,172.00
TOTAL	<u>24,320.00</u>		<u>9,728.00</u>	<u>14,592.00</u>


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JABALPUR

DATED: 22.04.2019

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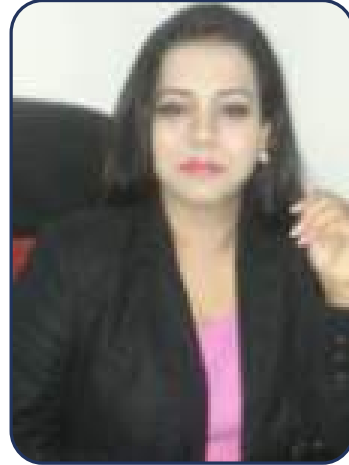


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THE SERRENDIP

A FOUNDATION OF FINDINGS AND APPLICATIONS
FOR PERSONS WITH AUTISM AND RELATED DISORDERS



Dr. Mary Temple Grandin is an American Professor of animal science at Colorado State University, consultant to the livestock industry on animal behavior and autism Spokesperson. She is one of the first individuals on the autism spectrum to publicly share insights from her personal experience of autism.

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