

# **Work Life Balance of Parents with Special Need Children**

**Ms. Rashmi R**

Assistant Professor Department of Management Studies  
Ramaiah University of Applied Sciences  
Bangalore, Karnataka, India  
[rashmi.co.mc@msruas.ac.in](mailto:rashmi.co.mc@msruas.ac.in)

**Heena Parveen, K S Punith Kumar**

Student, Department of Management Studies  
Ramaiah University of Applied Sciences  
Bangalore, Karnataka, India  
[heena0004@gmail.com](mailto:heena0004@gmail.com), [punithks2012@gmail.com](mailto:punithks2012@gmail.com)

## **Abstract**

Work-Life Balance is relatively undiscussed topic among the parents of special need children compared to parents of neuro-typical children. This article presents the results concluded by our own research aimed at determining factors influencing work-life balance in parents of special need children. The result is based on the analysis influence of total 25 variables categorized into 3 major factors: day-To-Day factors, work-life factors, occupational factors, personal factors. The study explores this topic by addressing factors influencing work-life balance and its hardship faced by parents of special needs children. The ultimate aim of our work is to raise awareness and inspire parents with special needs children to look at their specific hardships and stage in life to understand what type of work-life balance programs and emotional support they would need in an organization or their colleagues can provide. With context of management if an organization in terms of their employers, understands what extra support parents of special needs children need, they will be able to get maximum productivity from their employee.

## **Keywords**

Work-Life Balance, Parents, Special Need Child, Special Needs Parenting.

## **1. Introduction**

Building a sustainable work-life balance culture within a company is a win-win for all. Dr. Fredrick F. Reichheld is a renowned speaker at major business forums and has stated, "an increase in retention of just 5% can boost revenues 25% to 100%". In support of this, Forbes magazine has reported that not having work-life balance is one of the top 5 reasons employees do not stay with a company.

But what is Work-Life Balance? According to Susan Simmons, work-life balance means "bringing work, whether done on the job or at home, and leisure time into balance to live life to its fullest. It doesn't mean that spend half of your life working and half of it playing; instead, it means balancing the two to achieve harmony in physical, emotional, and spiritual health" (Simmons). This balance is especially important for employees with special needs children because of the below stated few problems.

### *Problem Statements*

Some of the major problems faced by parents of special needs children:

- Diverse Disabilities, Diverse Needs

No child is the same, even if they have the same handicap the type of special needs child a person has at home highly changes the type of work-life balance that is needed. Some people have special needs children who are hospitalized. There is also the difference as to whether a person's special needs child is mentally or physically handicapped or, in some cases, both. Depending on the type of disability, there are many specific issues that would affect one's work/life balance. For example, disabilities might require a round-the-clock caregiver, frequent hospitalizations, or frequent

trips to the doctor. This would require parents to be able to take more time off from work for either short or long periods of time.

- **Strained Relationships/ Divorce**

One additional life issue is the topic of divorce. Statistics for the overall percentages of people getting divorced according to *Enrichment Journal on the Divorce Rate in America*; is 41% for a first marriage, for a second marriage it's 60%, and for a third marriage it's 73%. A couple with a special needs child is even more likely to experience a divorce because there are many extra stresses on the parents and a lack of time to nurture the marriage since so much emphasis is placed on the child and his/her needs.

- **Siblings**

Another life issue associated with having a special needs child is the impact it can have on additional children. So much extra care and attention is focused on the child with the disability that oftentimes siblings get lost in the shuffle. This can cause feelings of jealousy and anger, which can lead to feelings of guilt. On the positive side, siblings may become more sensitive to others and less self-centered than they otherwise would have been.

## **1.1 Objectives of the Study**

The purpose of this thesis is to show that establishing a work-life balance, especially among parents with special needs children, is essential to both the health and production of a company.

The objectives of our work include:

- To identify the factors influencing work-life balance among parents with special needs children.
- To look at specific hardships in life of special needs parents and understand the type of work-life balance programs/Support they need.
- To assess viability of providing support to such parents in an organization during specific hardships stage in their life.
- To raise awareness and inspire parents with special needs children.

## **2. Literature Review**

With initial studies in the area of Work-Life Balance dating back to the 1970s, researchers from numerous disciplines have studied Work-Life Balance (Allen 2013). Work-Life Balance is an individual's perception of the fit between work and family roles (Allen 2013). It is often viewed as the lack of work-family conflict, a type of inter-role conflict that occurs because aspects of one's work and family roles are not compatible with each other.

From this field of research emerged concepts of Work-Life Balance among parents of children with special needs. With initial research in this area beginning in the 1990s, the number of studies exploring Work-Life Balance among this group of parents has recently begun to increase. Examinations of the experiences of these parents is important.

Here, we conducted a literature review on research examining Work-Life Balance among employed parents of children with special needs including developmental disabilities (e.g., Autism Spectrum Disorders (ASD)). Reviews of emerging fields of research, such as this one, are important because they allow for a broad understanding and synthesis of the research and set a research agenda. With this in mind, we listed number of objectives in conducting this review which, to our knowledge. First, we identify broad characteristics of the literature. Second, we attempt to synthesize the research in this area using the existing framework from the mature research Work-Life Balance to examine how individual and organizational factors impact Work-Life Balance among parents of children with special needs. Third, we discuss existing gaps in the literature so that suggestions for future research can be made. An additional objective is to discuss how existing policies may need to be altered to better assist these families. Finally, we identify ways that practitioners can better assist these families.

Children with disabilities be is neurological or physical have challenges in meeting their needs, so they need the assistance from a primary caregiver usually one of the parent (Gomez and Gomez 2013). Based on one of the study outcome of United Nations (UN) in 2016, there are 10% of children with special needs from the total population of children in the world (Desiningrum 2016). Children with special needs have dependency behavior to meet their day to day needs (Bariroh 2018). This dependency behavior can create stress especially for the primary caregiver / parents (Moawad 2012). Stress experienced by Special Needs parents can go along with the in impacting development of children with special needs (Smith and Grzywacz 2014). The stress of continuous care giving can cause permanent impact in the quality of life in parents of children with special needs (Murray et al. 2013).

Typically, presence of children is an encouragement source in the family, but the presence of children with special needs in the family causes more friction in relationship and stress among the primary caregivers (Moawad 2012). The development of children with special needs are dependent on the mental peace and stability within the family (Smith and Grzywacz 2014). Unfortunately, due to lack of awareness and societal set up the caregiving for children with special need in increasingly stressful (Moawad 2012). The primary cause of stress is usually the demanding hours of caregiving and the cost involved in caregiving, therapies and medication (Smith and Grzywacz 2014). When parents or caregivers are exposed to such stress for a prolonged period it possesses increased risk of health problems both physical and mental (Smith and Grzywacz 2014).

Based on this it can be inferred with the increased need to study the relationship of the stress of caregiver with the work life balance they have.

### **3. Methods**

The mixed method study (both the quantitative and qualitative methodology) is followed to understand “Work-Life Balance of Parents with Special Need Child”.

During In-depth interviews: The topics explored included responsibilities related to work and to caring for a child with Special needs employer policies.

#### **A. Introductory Questions**

First, knowledge about parent’s experiences in juggling work and family.

##### **a) Family**

It includes questions related to family:

- 1) How many children do you have? In general, how are your children doing?
- 2) What are your child’s symptoms? How long has your child had this condition?
- 3) How do you take care of your child who has this condition? How often do you do Therapist’s visits? How does the child manage daily tasks related to the condition?
- 4) What’s your typical weekday like?
- 5) What’s your typical weekend like?

##### **b) Work**

Then related with the job part.

- 1) What is your job title (current or most recent job)? Can you tell me what you do in a job? What do you like? What do you dislike?
- 2) Would you talk about your partner and her/his work?

#### **B. Core Questions:**

##### **a) Policies**

- Is your work hours flexible (e.g., are you free to set your own schedule)? Would you please give me some examples of how you might use this flexibility to handle family issues?
- How much control would you say you have in scheduling your work hours? How do you manage your time?
- Can you take time off easily to care for your child with Autism? How difficult is it for you to care for this child?
- Do your co-workers help you to manage your work and personal or family life?
- Does your company have a service that helps employees find child care if they need it?
- What do you think about the policies of your company such as flexibility and paid leave or help with child care and other services?
- Do you think you will still be working for this company one year from now?

##### **b) Issues by Time Sequence:**

- Did you take a leave for this child?
- If you have a plan to take a leave, what concerns do you may have now?

- Have you taken a long leave? Maximum how long it is?
- If you did not take a leave, have you changed your work schedule in any way?

**c) Work-Life Satisfaction:**

- Who helps to take care of this child? Do you have close relatives to help you care for this child?
- Do other family members/friends/neighbors help you care for this child? Do you have other care givers or baby-sitters? Are you satisfied with how they help with this child?
- Do you have professional help caring for this child? Are you satisfied with how they help with this child?
- How difficult is it for you to care for this child?

**d) Mood, Emotional Well-Being, and Health:**

- When you learned that your child had autism, how did this affect you?
- Do you feel stressed about work-family issues?
- Do you feel time pressure? What would help alleviate your time pressure?
- How is your health these days? Do you have symptoms as a result of the burden of caring for this child?

## **4. Data Collection**

Data collected via two methods:

1. In-Depth Interviews with working parents of special needs child in Bengaluru  
[Questions being asked during in-depth interviews mentioned in 3.Methods.]

2. Survey Google form filled by such 62 parents.

While survey Google form included question based on total 25 variables; categorized into 3 major factors:-

- Day-To-Day Factors
- Work-Life Factors/ Occupational Factors
- Personal Factors

## **5. Results and Discussion**

Qualitative study performed for Day-To-Day Factors and Occupational Factors. While for the personal factors quantitative methods were used.

Qualitative study are the subjective health indicators, such as quality of life, life satisfaction, stress, and leisure. For our collected data results of Qualitative study were satisfactory- on an average overall they were positively rated by approximately 40% of respondents but, to take care of the child at home and to meet the added expenses of having a child with special needs they had to do overtime at their workplace.

Results of Quantitative study is below:

- To check data distribution Frequencies and Percentage Distribution for each independent variables calculated. The findings were as:
  - Gender  
Male are the maximum respondent of the survey with approx. 55%
  - Area  
71% of our participant are from urban area.
  - Employment Status  
Most of the participants are private employed; while frequency of self-employed and government employed almost equal.  
As the reason of being unemployed among 62 respondents, 48% states that being parent of special need child, demands more care giving responsibilities thus stopped them to seek for job.
  - Work Time  
73% are working full time
  - Family Support in Childcare and in Housework  
The parents of special needs child get both kinds of help i.e., childcare and housework help only up-to some extent.

- To find out if there is a significant relationship existing between any two nominal (categorical) variables Chi-Square test done. It is found that chi-square value of Gender and Unemployment Cause is higher (4.972), so more likely it is significant.
- Correlation between the independent variables calculated to find out if any two variables are highly correlated. From the correlation matrix it is found that
  - Employment Status with Work Time,
  - Family Support in Childcare with Gender and
  - Difficulty in Finding Reliable Help with Area had strong relationship.
- Multiple Regression Model built. It indicated
  - Finding Reliable Help is having highest standardized beta value thus the most contributing variable and could be considered as a ‘Risk Factor’.
  - Partner/ Spouse Support and Family Support in Childcare are next important factor which can be considered as ‘Protective Factors.’
  - Remaining Factors, such as age, gender, educational status, area, work time etc., were not significant in predicting work life balance of parents of special needs in the multivariate context.

## 5.1 Numerical Results

Chi-Square of dependent variables with gender as independent variables were calculated (using JMP) (Table 1).

Table 1. Chi-Square Value

Age	Chi-Square Value
Below 30	0.08
31 to 40	
Above 40	
<b>Educational Status</b>	
Higher Secondary	1.85
Diploma	
Undergraduate	
Postgraduate	
<b>Area</b>	
Urban	2.21
Rural	
<b>Employment status</b>	
Government employed	1.13
Private employed	
Self employed	
Unemployed	
<b>Work Time</b>	
Full time	2.98
Part time	
<b>Work Type</b>	
Regular	0.89
Flexible	
Shift work	
<b>Unemployment Cause (child special needs)</b>	
Yes	4.97
No	
Maybe	

Hypothesis test for unemployment cause:

Assumption:

The null hypothesis for this test is that there is no relationship between gender and unemployment cause.

The alternative hypothesis is that there is a relationship between gender and unemployment cause (Figure 1-7).

Below is the chi-square output for gender and unemployment cause obtained using JMP (Table 2).

Correlation Matrix of all the variables (Table 3):

Table 2. Correlation Matrix

	Gender	Age	Area	Employment status	Work Time	Work Type	Unemployed cause	Availability of paid help.	Partner/Spouse Support	Difficulty in finding reliable help	Satisfaction with care
Gender	1.0000	-0.2738	0.4517	0.0649	-0.1582	0.4891	0.2085	0.2945	0.0858	0.2165	-0.0158
Age	-0.2738	1.0000	-0.0933	0.6688	0.8243	0.0269	0.2891	0.0810	-0.1462	0.2691	0.0625
Area	0.4517	-0.0933	1.0000	0.1609	-0.0822	0.4608	0.3035	0.1444	0.0755	0.6719	0.0755
Employment status	0.0649	0.6688	0.1609	1.0000	0.8936	0.3379	0.6728	0.4342	-0.1583	0.5413	0.0524
Work Time	-0.1582	0.8243	-0.0822	0.8936	1.0000	0.1939	0.5436	0.3602	-0.1811	0.3582	-0.0307
Work Type	0.4891	0.0269	0.4608	0.3379	0.1939	1.0000	0.6866	0.8620	-0.0457	0.6764	-0.0573
Unemployed cause	0.2085	0.2891	0.3035	0.6728	0.5436	0.6866	1.0000	0.7413	-0.1036	0.7214	-0.0933
Availability of paid help.	0.2945	0.0810	0.1444	0.4342	0.3602	0.8620	0.7413	1.0000	-0.0910	0.5441	-0.1144
Partner/Spouse Support	0.0858	-0.1462	0.0755	-0.1583	-0.1811	-0.0457	-0.1036	-0.0910	1.0000	-0.0106	-0.0164
Difficulty in finding reliable help	0.2165	0.2691	0.6719	0.5413	0.3582	0.6764	0.7214	0.5441	-0.0106	1.0000	0.0358
Satisfaction with care	-0.0158	0.0625	0.0755	0.0524	-0.0307	-0.0573	-0.0933	-0.1144	-0.0164	0.0358	1.0000
Family Support in Childcare	0.7859	-0.6027	0.4184	-0.2167	-0.4595	0.3419	0.0643	0.1637	0.0983	0.0469	-0.0792

The correlations are estimated by Row-wise method.

Table 3. Multiple Linear Regression (MLR) Model

	B	Beta
Area	-1.311	-0.064
Work Time	0.08	0.03
Work Type	0.97	0.085
Unemployed cause	-0.544	-0.03
Family Support in Childcare	-0.312	-0.161
Family Support in housework	1.531	0.052
Availability of paid help.	0.439	0.009
Partner/Spouse Support	0.728	0.163
Difficulty in finding reliable help	0.827	0.189
Satisfaction with care	0.109	0.081

## 5.2 Graphical Results

Do you get a lot of leisure time?  
62 responses

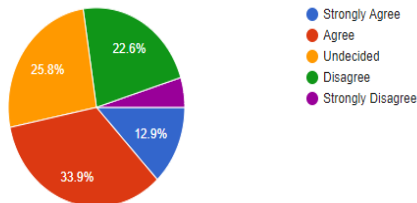


Figure 1. Leisure Time

How would you like to rate your Work-Life Balance?  
62 responses

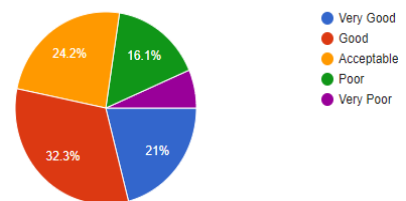


Figure 2. Rating of Work-Life Balance

How often do you get time to spend on different activities (Any activities which are totally different from your routine)?  
62 responses

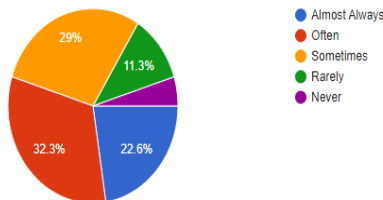


Figure 3. Time Spent on other Activities

How would you rate your quality of sleep?  
62 responses

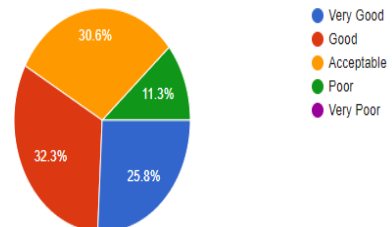


Figure 4. Quality of Sleep

Rate your satisfaction level on your work environment  
62 responses

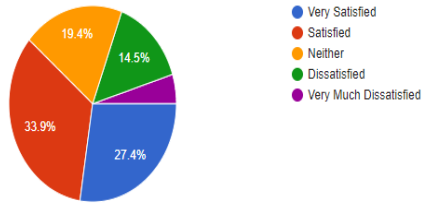


Figure 5. Satisfaction at work environment

Did either of you work longer hours to meet the added expenses of having a child with his condition?  
62 responses

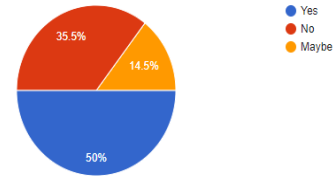


Figure 6. Extra Working Hour

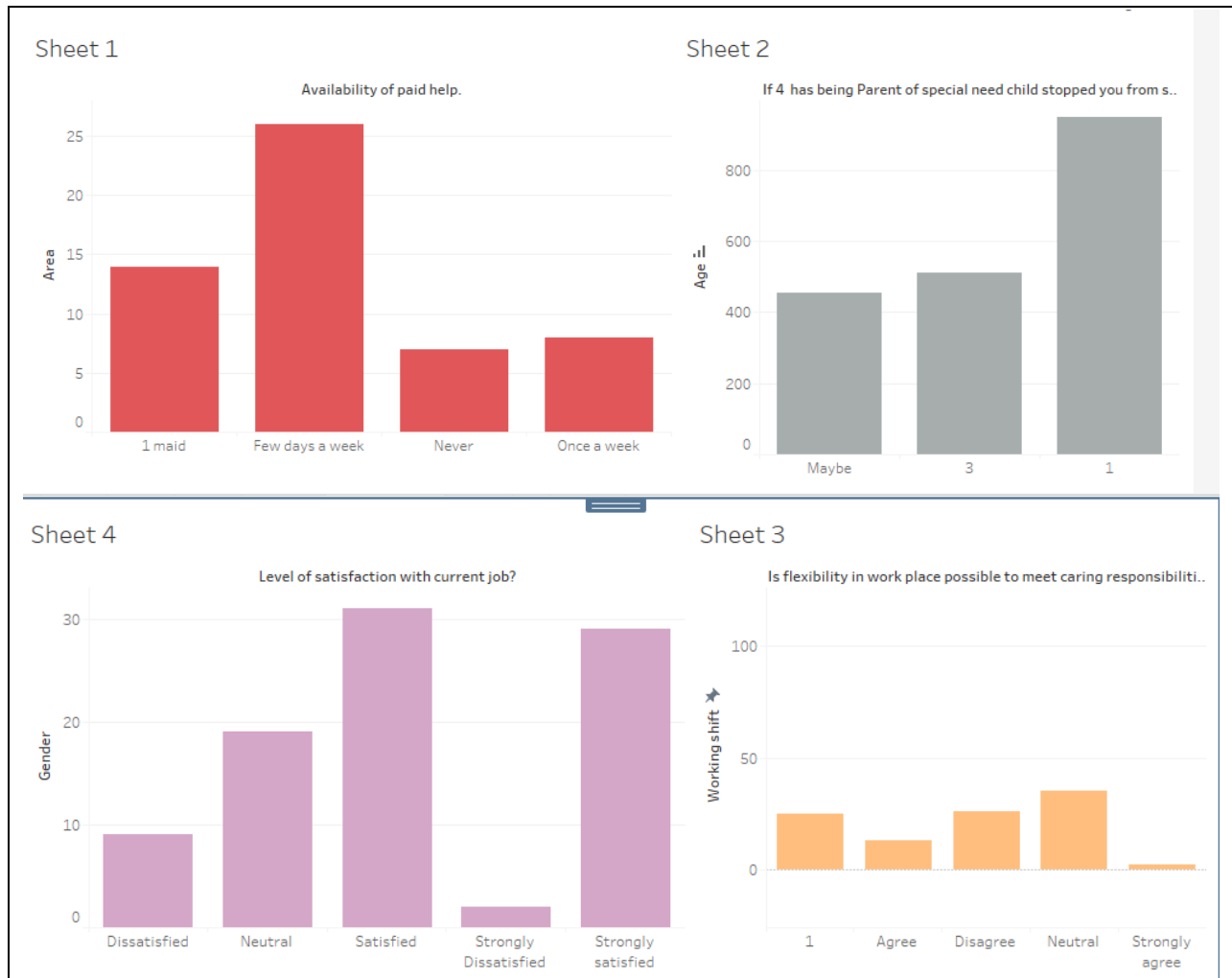


Figure 7. Interactive Dashboard

(Sheet 1: Availability of Paid Help VS Area

Sheet 2: If Unemployed has being Parent of Special Need Child stopped you from seeking employment VS Age

Sheet 3: Level of Satisfaction with Current job VS Gender

Sheet 4: Flexibility in workplace possible to meet caring responsibilities VS Working Shift)

## **6. Conclusion**

From this study, we will hopefully see that the work-life balance is a lot more entailed when a special needs child is involved. Employees with special needs child need to know what specific work-life balance programs they need to be able to work. They can do this by understanding what extra hardships are in their lives, and by being realistic at what stage they are at in life. A lot of these decisions will revolve around the type of special needs child they have. Employees will also need to understand that companies will not always offer those programs, so it is important to evaluate everything and make clear distinctions between needs and wants.

On the other hand, employers need to know just what their expectations of their employees are, so that they will know if the employee is reaching them. They also need to know what time and effort they are willing to put into establish work-life balance programs, and which programs fit well with company policies and are beneficial to the company. Employers will see that while it might take extra work-life balance effort to hire a parent of a special needs child, it can still be beneficial and the employee can still have maximum performance in the company.

The purpose of this paper was to show that establishing a work-life balance, especially among working parents with special needs children, is essential to both the health and production of a company. Successful organizations are those that understand the hardships faced by parents of special needs children, create programs that help their employees attain balance between work and life, and understand their employees' needs at different stages of their lives.

### **6.1. Recommendations**

Our study solely focused on the Work-Life Balance of Parents with Special Needs Children, and did not include any comparison group (e.g., parents with typical children). Prior research in this field suggested that the experiences of these employed parents are distinctively different from employed parents of typically developing children; particularly in their ability to find appropriate child care. However, it would be beneficial to compare the demands, resources, and strain outcomes of working parents with special needs children to working parents caring for a typical child.

The sample encompassed a diverse group of working parents caring for children with special needs. We interviewed parents through support groups in Bengaluru Karnataka. However, this method of recruitment meant that any parent who are not associated to these support groups (or who choose not to be part with them) were not included in this study, thus restricting the range of types of parents we sampled.

Considering the geographical location surveyed and the number of parents available in that location, this result is derived. Thus, the results might get changed based on different location and the increase sample size. Also, the data for this study was gathered using only a self-report survey questionnaire, which may lead to Mono-Method Bias. Mono-method bias may have inflated the strength of the observed relationships among demands, role-specific strain, between-role strain and resources. So, in this context proposed future improvement is, data should be gathered through multiple sources (e.g., from both parents, observation, location etc.)

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## **Biographies**

**Ms. Rashmi R** works as an Assistant Professor in the Department of Commerce, RUAS. Her aim is to help students find and nurture their strengths in order to reach their highest potential. She has taught modules dealing with Financial Management, Corporate Valuation, Investment Analysis and Portfolio Management, Rural Banking and Micro Finance, Business Economics, Business Environment and Entrepreneurship Development. Some of her time at the university is taken up as a Thesis Advisor for postgraduate (MS) students. She has acquired about 6 years of professional experience in total. She has been active in researcher in the area of Branding and marketing Analytics.

**Heena Parveen** is a final year MBA student in Business Analytics at M S Ramaiah University of Applied Sciences, Bengaluru. She has done graduation in Bachelors of Science in Zoology specialization from JPU, Bihar. Her research interests lie in domain of big data analytics.

**KS Punith Kumar** is a final year MBA student in HR Management at M S Ramaiah University of Applied Sciences, Bengaluru. He has done graduation in ECE from VTU College. His interests lie in HR Compliance and Talent Management.