CHAPTER 1
INTRODUCTION

1.1 CONTEXT OF THE STUDY
1.2 NEED AND SIGNIFICANCE OF THE STUDY
1.3 STATEMENT OF THE PROBLEM
1.4 OBJECTIVES
1.5 HYPOTHESES
1.6 OPERATIONAL DEFINITIONS OF KEY TERMS
1.7 METHOD ADOPTED
1.8 SCOPE OF THE STUDY
1.9 DELIMITATION
1.10 SUMMARY
INTRODUCTION

1.1. CONTEXT OF THE STUDY

We live in a world of diversities. Every form of living and non-living being is quite unique and different from each other. At times we lack words to appreciate the unimaginable creativity of God when we find that no single creation of His is an exact replication of the other. As a result, a child comes to this earth with its own unique abilities and capacities of body and mind. Some are fortunate enough to have extraordinary abilities or capacities, while others are averages or even suffer from so many deficits and deficiencies since from the birth. This gap between the abilities and capacities of the children related to their learning, adjustment and development found at the time of birth may further be widened by the nature of the environmental differences encountered by them in their nourishment and education.

In a society of competing dualisms between rich and poor, urban and rural, developed and undeveloped, it is not hard to imagine the conditions and challenges that the most vulnerable members of society face. There are certainly many vulnerable groups present in India, but one of the easiest to forget are the 31 million individuals with Intellectual Disabilities (ID) in India (WHO, 2004).

The American Association on Mental Retardation continued to use the term mental retardation until 2006 its members voted to change the name of the organization to the “American Association on Intellectual and Developmental Disabilities,” rejecting the options to become the AAID or AADD.

Though intellectual disability is the widely used terminology to refer to persons having an arrested and incomplete development of mind, mental retardation is still the legally recognized terminology in our country (RCI, 2012). But it’s not used as much because it hurts people’s feelings. Instead,
Introduction

Mini Mathew

you might hear terms like “intellectual disability” or “developmental delay”. But all these words mean basically the same thing. Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, as expressed in conceptual, social, and practical skills. This disability originates before the age of 18 (AAIDD, 2012).

Children with intellectual disabilities (sometimes called cognitive disabilities, mental retardation, differently abled, mentally challenged, etc.) may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They will learn, but it will take them longer. There may be something they cannot learn. Persons with intellectual disability vary in their reading skills and mathematical abilities. There is difficulty learning and thinking in abstract terms and adapting what she/he hear to everyday situations, attention, memory, self-regulation, language development, academic achievement, social development and motivation, communication, peer relationships, community adjustment, leisure and work, imagination and foresight, self-care, home living, self-direction health and safety, etc. A person with intellectual disability has needs, desires and joys like most of us and wishes to succeed.

Persons with intellectual disability have the following problems: they have difficulty solving complex problems, develop slower, so by the time they are grown they have fallen behind other adults, they have more trouble than most people making it on their own, they may need more time to adjust to a job, like any other worker she/he may need time to become friendly, and in new or unfamiliar environments she/he may resist changes and have trouble following directions. The problem behaviour mentioned in Behavioural Assessment Scales for Adult Living- Mental Retardation (BASAL-MR Part B) are physical harm towards others, damages property, misbehaviours with others, temper tantrums, self-injurious behaviours, repetitive behaviours, odd behaviours, inappropriate social behaviours, inappropriate sexual behaviours,
rebellious behaviours, hyperactive behaviours, and fears (Peshawaria et al., 2000).

In India as per the National Census 2011 the disabled population is 2.1% that comes to 2, 68, 10,557 and the male female ratio is 58:42. The Planning Commission of India in the 11th Five Year Plan estimates that 5 to 6% of the population has disabilities. The above figures show that in India a significant portion of the population are having disabilities. According to the 2011 census in Kerala there are about 7, 61,843 disabled persons and the male population is 51.81% and female population is 48.19%. The persons with disabilities deserve proper care, protection, training, employment and rehabilitation (Disability Census, 2014-15).

Persons with Intellectual Disability can do work and are able to hold steady jobs - if properly trained and placed in the right job. They succeed in tasks that are well explained. Most will try hard and stay with their jobs; they usually have a very good attendance record. They show a desire to learn as well as loyalty and pride in their work. There are many types of jobs they can do well; such as factory work, construction, clerking, truck driving, carpentry or painting.

Ghai (2002) conducted a study to understand how contact and exposure have influenced the public’s perceptions of people with ID. The public was asked questions about the capabilities of individuals with ID. Overall, the respondents significantly underestimated what individuals with ID can do, and seemed to view individuals with ID as being more moderately to severely impaired. That is, those surveyed from India perceive individuals with ID as being limited in their ability to perform not only complex independent living skills, but also the more simple self-help skills. In terms of self-help skills, the respondents underestimate the ability of individuals with ID to perform simple activities like washing and dressing, following directions or engaging in a simple conversation. Only half, or even less than half of those surveyed
believe that individuals with ID can engage in these activities. Further, and not surprisingly, less than 30% of those surveyed believed that individuals with ID are able to carry out more complex skills such as handling money, using public transportation and acting appropriately with strangers. In actuality, the vast majorities of persons with ID is mildly impaired, and are able to carry out almost all self-help skills, interpersonal skills and even some complex independent living skills. These findings further illustrate the stereotype that exists among the Indian public that individuals with ID are less capable than their non-disabled peers and are more comparable to children.

Adults with mild mental retardation lives and works in community may not be identified as retarded, adults with moderate mental retardation performs semiskilled work with supervision; may achieve competitive employment, adults with severe mental retardation can contribute to self-maintenance with supervision in work and living situation, and adults with profound mental retardation may acquire some communication skills; care for basic needs; may perform highly structured work activities.

According to National Center on Workforce and Disability, NCWD, (2008) the following are the basic etiquette of Persons with Mental Retardation;

- Persons with mental retardation are not "eternal children." Adults with mental retardation should be treated and spoken to in the same fashion as other adults. Do not "talk down" to a person with mental retardation. Assume that an adult with mental retardation has had the same experiences as any other adult.

- Like everyone else, individuals with mental retardation are extremely diverse in their capabilities and interests. Avoid stereotypes, such as the assumption that all people with mental retardation enjoy doing jobs that are repetitive, or want to work in fast food restaurants or supermarkets.
• Many individuals with mental retardation can read and write. Don't assume that a person with mental retardation lacks academic skills, such as reading, writing, and the ability to do mathematics. While an individual's disability may significantly impact these areas, many people with mental retardation have at least some level of these academic skills.

• Even if their academic skills are limited, they still have much to share and contribute. A low level of academic skills does not mean that they don't have valuable ideas and thoughts. Provide opportunities for persons with limited academic skills to contribute verbally, and take what they have to say seriously. Ensure that persons who have difficulties reading or writing have equal access to written materials (for example, by taping them or having someone review the materials with them orally). Use pictures or simple photographs to identify rooms, tasks, or directions.

• Treat the individual as you would anyone else. If engaging in a conversation with someone with mental retardation, bring up the same topics of conversation as you would with anyone else such as weekend activities, vacation plans, the weather, or recent events.

• Giving instructions. Persons with mental retardation can understand directions if you take your time and are patient. Use clear language that is concise and to the point. When giving instructions, proceed slowly, and ask the person to summarize the information, to ensure that it has been understood. You may have to repeat yourself several times in order for the individual to take in all the information. "Walk through" the steps of a task or project. Let an individual perform each part of the task after you explain it.

• Don't defer to a staff person or caregiver. When a person with mental retardation is accompanied by another person such as a staff person, caregiver, or family member, don't direct questions and comments to them.
Speak directly to the person with mental retardation. Also, don't allow someone else to speak for the person with a disability.

- Avoid the term “mental retardation." If you need to speak about a person's disability, persons with mental retardation prefer the term "developmental disability" rather than "mental retardation." (Mental retardation is one type of developmental disability.)

Young adults with mental retardation enter the adult world with many of the same expectations as young adults without mental retardation. Levinson and Levinson (1996) cited young adulthood as a very dramatic time of one’s life. For many it is a time of great vitality and fulfillment; it represents a time when life tasks and goals are outlined and pursued. Establishing and maintaining friendships, a career, and a residence are important tasks in the lives of most young adults, regardless of level of functioning.

Traditional beliefs that persons with intellectual disability stopped learning by the time they reached high school had limited the extent of their education. A focus on vocational and daily living skills excluded any meaningful instruction in literacy and stopped individuals with intellectual disability from the opportunity to reach their full potential at school and beyond. Jobling and Moni (2001) found that, with the right teaching, young persons with intellectual disability could not only continue to increase their literacy skills but also develop the ability to use these skills in new and varied situations.

Functional illiterates, older youths and adults can read, but to such a limited extent that they cannot understand basic written information needed to function in adult daily life. They may be able to read easy primary-level stories, but be unable to cope with personal or business letters, traffic signs, writing found on packages, medicine bottle labels, application forms, advertisements, bills, maps, telephone books, recipes, or newspapers. Job related reading, which was found by Gutherie and Kirsch (1987) to constitute
a large part of all reading by adults, offers another functional literacy problem. Literacy demands in some workplaces may actually be greater than those required in the daily reading of students in school. In many cases, students read less often in instructional settings than workers do on the job, and school reading frequently involves easier material that can be read with less depth than that required in the workplace. Occupational effectiveness may be determined by literacy level.

A significant factor, which drew much professional attention in the early days of the transition movement, was the data generated from various adult outcome studies conducted in the late 1980s and early 1990s. These studies substantiated a picture of unemployment, long-term underemployment for those individuals with jobs, minimal participation in postsecondary education with even bleaker completion rates, few individuals living independent lives, limited social lives, and little community involvement (Hasazi et al., 1985; Mithaug et al., 1985).

Teachers have identified the need for functionally oriented curricula as an important way to improve instruction for students with disabilities at the secondary level (Halpern & Benz, 1987). The importance of functional curricula has also been recognized and championed by the Division on Career Development and Transition (Clark et al., 1994).

Wagner and colleagues (1993) collected data on how well curricular efforts are developing everyday living skills across disability areas; it is startling to note that a substantial percentage of this group, as perceived by parents, do not demonstrate adequate functional abilities in the areas of self-care skills (67.4%), functional mental skills (32.8%), and community living skills (29.4%). Most professionals would agree that (a) these skills are important for dealing successfully with the demands of adulthood, (b) these skills should be taught in school, and (c) proficiency should be demonstrated prior to students exiting the system.
From Edward Seguin in the 1850s’ to Richard Hungerford in the 1940s, to the present professional focus on transition to adulthood, practitioners in the field of mental retardation have recognized the need to prepare each student to be a contributing member of society. Seguin firmly stated that occupational preparation should have a place in educational programs. Professionals in special education, general education, and vocational education, whether optimistic or pessimistic about career programming for individuals who are mentally retarded, need to move forward in the development of stronger career preparation programs that prepare such individuals to be gainfully employed and to fit naturally into their communities. Today many practitioners are seeking to provide more realistic vocational training for students with mental retardation, to integrate them into regular vocational education training programs and to assist them in making a successful transition from school to work (Smith et al., 2002).

Transition education includes knowledge acquisition and skill development across a number of important areas: academic skills, academic support skills, social/personal behaviours, life skills, self-determination, career development, and vocational preparation. These are important however some important topics are often not addressed. Patton et al., (1997) point out this oversight: “consideration of specific content that must be taught to maximize students’ chances for successfully dealing with the demands of adulthood and methods for teaching this content have been largely overlooked”

Since the goals of career development are appropriate for all students, career goals for students who are mentally retarded should be similar to goals for those who are not. However, the nature of these goals may vary as a function of each individual’s general and specific characteristics. Individual whose support is minor or nonexistent should be capable of independent living as adults.
Without question, adults who are mentally retarded are capable of being successful workers and making successful community adjustments. Being a successful worker and functioning successfully in the community are consequences of learned behaviours. We can analyze these learned behaviours in terms of the skills and knowledge needed for successful functioning and teach them as part of a comprehensive career education programme. Individuals who have extensive needs can likewise make successful adjustments to society and become contributing members of their communities. For example, workers with moderate and severe retardation have been successfully placed in competitive employment settings, performing such jobs as kitchen utility worker, porter, elevator operator, dishwasher, groundskeeper, janitor, and assembly line worker (Smith et al., 2002).

The key to the success of competitive employment for individuals who need significant levels of support appears to be appropriate training and ongoing job assistance. Although programmes differ in the type of ongoing work support provided, Bellamy and Horner (1987) note that successful programs usually have four common elements: (a) use of systematic approaches to training and maintaining work behaviours; (b) focus on work opportunity over work preparation; (c) emphasis on social integration with coworkers, customers, and others in the workplace, and (d) definition of programme success in terms of wages and work benefits.

To prepare students for the challenges that will face them when they leave school, efforts must be focused on teaching them life skills that will facilitate their inclusion as contributing members of their communities and their successful adjustment to adulthood. The major functional domains of adulthood in which all of us must demonstrate some level of competence are employment education, community involvement, emotional physical health, home and family, leisure pursuits and personal responsibility and relationships. Two important elements are crucial to providing life skills content to students: (a) identification of appropriate life skills that are locally
referenced and culturally appropriate and (b) provisions for covering appropriate skills within existing curricular options.

The complexity of each person’s life, variety of experiences, and opportunity to assume responsibility all depend on such things as the availability of community resources, community attitudes, and the characteristics of the people involved. Schalock and Kiernan (1990) have identified home, work, and recreational /leisure environments as the three major environments in which people operate, yet they contend that it is actually the community environment that unites all three.

Sexual development and sexual activity may comprise the most controversial issues pertaining to adults with mental retardation. The sexual development of persons with mental retardation is, for the most part, no different from that of person without mental retardation. Many professionals argue that sexual development and sexual activity are a normal part of daily living and that the right to sexual expression should not be prohibited. Others disagree, citing a number of unfortunate and even life-threatening consequences of sexual activity as possible outcomes— for example, exploitation, unwanted pregnancy, sexual and physical abuse, and sexually transmitted diseases (Schwier & Hingsburger, 2000).

A number of factors make the right to socially appropriate sexual activity and sexual expression a bit more difficult. These include the heightened supervision and supports in comparison with individuals without mental retardation; lack of accurate information typically provided by service providers about sexual development and functioning; and fewer socialization opportunities in which to try out new behaviours, roles, and expectations. Something as simple as negotiation the boundaries between risk and opportunity for growth remain a paramount issue for adults with mental retardation (Schwier & Hingsburger, 2000). Increased independence and current patterns of social interaction now evidenced in the community.
necessitate, in practical terms, that the issue of sexuality no longer be ignored (Sundram & Stavis, 1994).

There are a number of demands that are faced by parents of an adult child with an intellectual disability. Some of these are also faced by parents whose children follow a typical developmental pathway (although generally the demands are experienced over a shorter time span), and others are shared by carers in different circumstances, for example, one spouse caring for another. Many parents need to provide assistance with the daily tasks associated with living – feeding, dressing, toileting, and mobility. Physical health care needs will be paramount for some families while for others their priority may be managing the consequences of mental health problems such as depression and dementia. These latter problems increase in the population of adults with an intellectual disability as they age (Janicki & Dalton, 2000; Prasher & Cunningham, 2001) and increase the demands on those caring for them.

Parents are regularly placed in the position of having to advocate for their child to obtain appropriate services and/or to maintain the quality of services to their child. Of particular interest to parents of adult offspring with an intellectual disability is out-of-home living and services that provide daytime activities (Haverman et al., 1997; Minnes & Woodford, 2005). Australian families interviewed by Llewellyn et al., (2004) had a number of concerns related to services. Some of these had to do with current frustrations with services – inadequate provision, poor relationships with staff, a perceived lack of recognition of their expertise in relation to their son’s/daughter’s needs and character, inexperienced staff and frequent staff turnover. Parents also had constant concerns about the future, fearing changes to service provision, either as a response to policy or funding changes, or services becoming unwilling to continue to provide for their child due to behavioural difficulties, complex health needs or deterioration in function.
1.2. NEED AND SIGNIFICANCE OF THE STUDY

There are different Acts developed in India for persons with disabilities like Rehabilitation Council of India Act, 1992; Persons with Disabilities Act, 1995; National Trust Act, 1999; United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2006. The process is going on to amend these Indian Disability Acts (Singh, 2013). However, services for adults with intellectual disability in India are still in a state of evolution. Presently majority of the adults in India remain unserved. Services for the adults with intellectual disability are generally restricted to sheltered workshop setup in special schools. These provide limited opportunities for training towards earning and independent living particularly within the family and community. Although, there are no follow up studies reported in India, review of the western literature indicates a high rate of unemployment among adults with intellectual disability. Studies also indicate that unacceptable personal appearance, inappropriate social interaction with others and behaviour problems are some of the major reasons for job loss among adults with intellectual disability (Peshawaria et al., 2000).

A key issue is the lack of attention to the needs of students with disabilities once they become too old to fall within the age limits of public school programmes. Such students are often poorly equipped to enter community living or to work after graduation, even after years of special education. Whereas school systems have compiled with many legislations for children with special needs in public school settings, comparable programs for young adult graduates have been less available than those for children. Although there are pitfalls and difficulties for all students in defining their “life course” after graduation, it may be that graduates with disabilities face more formidable barriers. Experience has shown that young adults with intellectual disability often need supportive services to completely move into
mainstream community life as adult citizens (Richardson et al., 1988; Shafer et al., 1987).

Priorities for services for adults who have graduate from special education programs now center on issues such as housing, employment, and community-based professional services. For school-aged individual still enrolled in public or private special education programs, the focus of services has shifted toward functional skill training, transitional programming, vocational and employment training and independence or community skill training. Although the principle of normalization has focused attention on the goal of independence as a service outcome for most persons with disabilities certain subpopulations of individuals still may require extensive specialized services. In that regard, the context of complete normalization of services in the least restrictive setting can be challenged (Crissey & Rosen, 1986; Walsh & McCallion, 1987).

Studies were conducted by researchers related to the functional reading, writing, and academic achievement and problems related to social, sexual, emotional and health aspects of children with intellectual disabilities. Review of various research works of different researchers it seems that in Kerala in the recent past no study has been undertaken to determine the functional abilities and problems of adults with intellectual disabilities. There are few studies conducted in Kerala with regard to functional academic skills of children with mental retardation (Preena, 2009) and functional socio-vocational skills of adults with mental retardation (Umadevi & Sukumaran, 2012). So the review of literature promotes the need of this study in Indian context. The current educational options are inclusion, integration and special school. At present the content of teaching in the above said educational options are not enough for transition from school to work, employment and independent life of persons with intellectual disability. The need of the hour is to ensure that educational system for persons with intellectual disability at all levels should
prepare them for future life. Hence it is highly relevant to conduct a study on the functional abilities and problems of adults with intellectual disability.

1.3. **STATEMENT OF THE PROBLEM**

The study is designed to find out functional abilities and problems of adults with intellectual disability. The present prospective study addresses the identification of the functional abilities related to six domains such as personal skills, food management skills, household tasks, community living skills, work related skills and functional academic skills of adults with intellectual disability, as well as the identification of the behaviour problems, sexual problems, emotional problems and social problems. This study is therefore entitled as: **Functional Abilities and Problems of Adults with Intellectual Disability**.

1.4. **OBJECTIVES OF THE STUDY**

1. To identify the level of personal skills of adults with intellectual disability.
2. To identify the level of food management skills of adults with intellectual disability.
3. To identify the level of household tasks of adults with intellectual disability.
4. To identify the level of community living skills of adults with intellectual disability.
5. To identify the level of work-related skills of adults with intellectual disability.
6. To identify the level of functional academic skills of adults with intellectual disability.
7. To study the functional abilities of adults with intellectual disability with respect to selected socio-personal variables.
8. To find out the extent of behaviour problems of adults with intellectual disability.
9. To find out the extent of sexual problems of adults with intellectual disability.
10. To find out the extent of emotional problems of adults with intellectual disability.
11. To find out the extent of social problems of adults with intellectual disability.
12. To study the problems of adults with intellectual disability with respect to selected socio-personal variables.
13. To identify the relationship between functional abilities and problems of adults with intellectual disability.
14. To find out the nature and extent of overall parental expectation on the life of adults with intellectual disability.
15. To study the parental expectation on adults with intellectual disability with respect to selected socio-personal variables.

1.5. HYPOTHESES

1. There is no significant difference in the functional abilities of adults with intellectual disability with respect to the difference in the socio personal variables.
2. There is no significant difference in the functional abilities of adults with intellectual disability with respect to the difference in their level of problems.
3. There is no significant difference in the problems of adults with intellectual disability with respect to the difference in the socio personal variables.
4. There is no significant difference in the problems of adults with intellectual disability with respect to the difference in their level of functional ability.
5. There is no significant relationship between functional abilities and problems of adults with intellectual disability.
6. There is no significant difference in the parental expectation of adults with intellectual disability with respect to the difference in the socio personal variables.
1.6. OPERATIONAL DEFINITIONS

For the purpose of clarity and simplicity, operational definitions of the important terms used in the present study are given below:

**Functional abilities:**

It refers to the skills needed for independent life such as personal skills, food management skills, house hold tasks, community living skills, work related skills and functional academic skills.

**Problems:**

A problem refers to any activity or response that is not acceptable to the society or the community.

In this study problems of adults with intellectual disability mean behaviour problems, sexual problems, emotional problems and social problems.

**Parental Expectation:**

In this study parental expectation refers to the earlier anticipation of the parents regarding the performance of their adult children with ID, especially in the areas like personal skills, food management skills, household tasks, community living skills, work related and functional academic skills.

**Adults:**

In this study the term adults refers to the persons with mild, moderate, severe and profound intellectual disability belonging to the age range of 18 to 45 years.

**Intellectual Disability:**

The term "intellectual disability" (ID) refers to the condition of individuals characterized by significant limitations both in cognitive functioning and adaptive behavior (conceptual, social, and practical adaptive skills) that originate before age 18.
1.7. METHOD ADOPTED

This study is intended to find out the functional abilities and problems of adults with intellectual disability. Descriptive survey design is adopted for this study. The study population is composed of adults with intellectual disability in Ernakulam and Kottayam Districts. The sample of the study consists of 200 adults with intellectual disability who belong to the age group of 18-45 years and attending special school, sheltered and open employment set up and those who are in the family without any training. The investigator categorizes the sample like mild, moderate, severe, and profound based on the ‘Disability Certificate’. Random sampling method is used to select the sample. The tools used are:

1. Socio Personal Information Sheet (SPIS)
2. Functional Ability Scale for Adults with Intellectual Disability (FASAID)
3. Problem Assessment Scale for Adults with Intellectual Disability (PASAID).
4. Parental Expectation Scale (PES)

Data collected in three stages; assessment and observation of adults with intellectual disability, interview with teachers and parents and assessment of the parents. The collected data are analyzed using appropriate statistical techniques and the results obtained are interpreted accordingly.

1.8. SCOPE OF THE STUDY

This study is expected to highlight the importance of functional abilities of adults with intellectual disability for their independent life. It is hoped that the descriptive survey nature of the study will help to identify the functional abilities, problems and parental expectations of adults with intellectual disability. Findings of the study may be indicative of the effectiveness of the existing special education system. The study is hoped to reveal hither to
unknown facts regarding functional abilities like personal skills, food management skills, house hold tasks, community living skills, work related skills and functional academic skills of adults with ID. Further, the study is expected to provide valid information regarding problems related to behavioural, social, emotional and sexual. All the domains included in this study are intensively related to the independent living and functioning of a person with intellectual disability. Hence, present study has the potential to unfold the status of functional abilities of adults with intellectual disability reflecting their level of independent life. The findings on degree of problems also can reveal to what extent the present educational practices are effective to prevent and/or to overcome these problems. In short, the present study has immense scope for a reappraisal of the curriculum of persons with intellectual disability.

1.9. DELIMITATION

The present study is limited to 200 adults with intellectual disability in Ernakulam and Kottayam districts in Kerala State.

1.10. SUMMARY

This study is an attempt to describe the functional abilities and problems of adults with intellectual disability. This chapter deals with the background of the study, need and significance of the study, objectives, hypotheses, operational definitions, method adopted as well as scope and delimitations of the study.