

## Quality of Life of Adults with Down syndrome in Virginia

Talat Allahyari<sup>1\*</sup> and Michael E. Wolf-Branigin<sup>2</sup>

<sup>1</sup>Department of social work, Allameh Tabataba'i University, Tehran, Iran

<sup>2</sup>Department of Social Work College of Health and Human Services, George Mason University, USA

\*Corresponding author: Talat Allahyari, Department of social work, Allameh Tabataba'i University, Tehran, Iran, Tel: 98 21 2222 3001; E-mail: Allahyari@atu.ac.ir

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### Abstract

**Background:** Quality of Life (QOL) has been developing in the field of intellectual development disability since the early 1980s, and ever since there have been research, models, and theoretical constructs along with many recommendations. Ignored in its early development, QOL is now seen as important for support and intervention. Down syndrome is the most common occurring chromosomal condition—one in 700 babies in the USA is born with it. Limited research has been conducted to study quality of life of adults with DS. The present study aims to describe the quality of life of adults with DS in Virginia.

**Method:** Qualitative approach was used to capture the “lived experience” from the perspective of those who live it and create meaning from it. This qualitative study investigated experts' and parents' thoughts and experiences of the adequacy of social service programs in Virginia which included health, rehabilitation, education, employment, and nutrition. Individual face-to-face or telephone interviews were conducted with five experts and five mothers of adult, aged 23 or older with DS. The interviews were analysed using content analysis.

**Results:** Indicated that from a service program perspective (health, rehabilitation, education, employment, nutrition), there is a discrepancy between presented services and unmet needs, namely shelter housing, recreation programs and limitations of City-University Energy-saver (CUE) buses.

**Conclusion:** Adults with DS are considered to have a low quality of life. This study illuminates four new insights yet there remain many challenges into acceptance, marriage, end of life and the present law concerning individuals with DS. The emerging question is: Does quality of life of adults with DS in Virginia depend on their acceptance into society, marriage, solving employment problems or the law on guardianship?

**Keywords:** Quality of life; Down syndrome; methodology; social work

### Introduction

Quality of life (QOL) has been developing in the field of intellectual development disability since the early 1980s, and ever since there have been research, models, and theoretical constructs along with many recommendations. Ignored in its early development, QOL, is now seen as important for support and intervention [1,2]. In many parts of the world, particularly in North America, Australia and Western Europe, the notion of QOL has become an important approach in theory, research, application and evaluation. One well-developed area is in the field of intellectual and developmental disabilities [3]. Abraham Maslow [4] published his book “Towards a Psychology of Being,” and established a theory of quality of life, which still is considered a consistent theory of quality of life. Maslow based his theory for development towards happiness and true being on the concept of human needs. He described his approach as an existentialistic psychology of self-actualization, based on personal growth. Since then there have been discussions on the definition of quality of life for people (without and with a disability). There are various discussions and different definitions about quality of life. Roy Brown et al. [5] stated that the definition of quality of life are many, but in the field of

intellectual and developmental disabilities there are a number of commonly accepted ideas, quality of life is:

- The social well-being enjoyed by people, communities and their society
- Both objective and subjective, involving material well-being, health, productivity, intimacy, safety, community and emotional well-being
- Experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings

It can also be represented by the discrepancy between ones needs and wants and the situation in which individuals find themselves.

“Down syndrome is the most commonly occurring chromosomal condition—one in 700 babies in the USA is born with it. There are close to 400,000 people currently with DS in the United States, and it is growing by about 6,000 per year. In 1958, Dr. Jerome Lejeune became the first to discover a link between an intellectual disability and a chromosomal abnormality. He subsequently opened the way to cytogenetic and modern genetics as we know them. In 1997, the Jerome Lejeune Institute opened in France, becoming the world's first specialized and paramedical consultation center to provide medical care for [individuals] with Down syndrome and other intellectual disabilities of genetic origin. The Jerome Lejeune Foundation USA was

established in 2011 to extend the mission of Dr. Lejeune to the United States” (Jerome Lejeune Foundation, 2017). According to the *American Journal of Medical Genetics Part A* published on 2017, in recent years 30% fewer babies have born with DS than there would have been if elective terminations were not available. In the US, almost three-quarter of expectant parents who learn prenatally that their child has Down syndrome choose to terminate the pregnancy. People with Down syndrome are known to have shortened life spans. In the last century, however, their life expectancy has dramatically increased from 9 years in 1929 to 60 years in 2002 [6]. Despite that they live longer than the past, to date, limited research has been conducted to study quality of life of adults with DS. The present study aims to describe the quality of life of adults with DS in Virginia. Individuals with Down syndrome attend school, work, and participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways. All individuals with Down syndrome experience cognitive delays, but effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses (Ibid). Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to lead fulfilling and productive lives (Ibid).

There are a range of theories about intellectual disability and about Down syndrome. The basic theories include the theory of normalization by Wolf Wolfensberger et al. [7] who stated that individuals with DS should lead an independent life as much as possible, and the social theory of disability by Fulcher G [8] who claimed that the society is responsible for the wellbeing of all people.

In this research, the real conditions of individuals with DS and their “unmet needs” were studied. As stated above, if there is a discrepancy between unmet and met needs, quality of life may be considered low. Since individuals with DS need service programs, the focus is on social services that their parents expect to receive for their children. Service programs are usually presented through welfare programs by governments in every country. In the present research, service programs include: health, rehabilitation, education, employment, and nutrition programs.

Health or medical care is one of the most important social service programs for individuals with DS. Babies born today with DS and their families can expect a lifetime of possibilities and potentials. The life expectancy for people with DS continues to rise – The median lifespan is now 58 years. Heart conditions, which can accompany DS, have been routinely and easily corrected by surgery since the early 1980s. Medications can solve co-occurring thyroid problems, and sleep apnoea can be stamped out with good surveillance and treatment options. Rehabilitation includes speech therapy, occupational therapy, infant stimulation programs, social skills in CAR, before school age and during school age. Education may include in mainstream schools or special classes or special schools. Children with DS have benefited educational theories. Phillips D [9] has conducted various research studies in the arena of educational policy and theoretical perspectives in comparative education. Employment is the process used by professionals and parents to encourage individuals to explore and take reasonable risks and chances. Finally, about nutrition, adults with DS often need to keep their weights at healthy levels, and yet the prevention and treatment of overweight among them are rarely addressed. The primary causes of their weight problems are environmental; degree of intellectual disability and congenital conditions play lesser roles [10].

## Methodology

A qualitative approach was used. Historically Fortune et al. [11], in 1994, the Council on Social Work Education (CSWE) required that qualitative research methods be taught in all accredited bachelor’s and master’s level social work programs, a requirement renewed in the Educational Policy and Accreditation Standards in 2002 and again in 2008 (CSWE2002, 2008). Social work research in the United States was transformed with the finding of the Society for Social Work and Research (SSWR) in 1995 at its inaugural conference in Arlington, Virginia. SSWR’s annual conference program reflected quantitative dominance but qualitative methods also had a strong presence (e.g. a workshop on narrative analysis conducted by Catherine Riesman was included in the first SSWR conference program) [2]. The international success of the *Journal Qualitative Social Work* is another manifestation of this phenomenon (Ibid).

## Method

The qualitative approach used was Phenomenology. Phenomenology research describes a ‘lived experience’ of a phenomenon. In Phenomenology, the researcher is committed to understand the social phenomena of participants’ experiences. The phenomena of interest in social service programs received from birth to adult living as perceived by experts and parents. In this study, the researcher’s personal connection to this inquiry was a parent of a beautiful adult with DS who has experienced transition from postsecondary education to employment.

The research reported in the present paper involved structured interviews with experts in the field of intellectual disability and mothers of adults with DS. Interviews were chosen as a well-organized method to gather experts’ and parents’ thoughts to the researcher. Structured face-to-face and telephone interviews were conducted with experts and mothers from 30 to 90 minutes. Standardized, structured interviews require the development of specific questions that are asked of everyone participating in the research study. The assumptions are that the questions asked are sufficiently comprehensive to get all the information desired and worded well enough for all to understand [11]. Questions compiled based on a review of the literature, and the combined experiences of the authors in the arena of DS. As a result, the interview guide involved questions that allowed experts describe available services and who, in practice, receive it. Mothers describe their experiences as they related to the young adult’s transition into adulthood across a range of life areas. With the experts’ and mothers’ permission, the interviews were recorded and then transcribed. The interviews were analysed using content analysis. Transcripts were read several times during the analysis to ensure that data fit with analysis findings and also to assist in ensuring trustworthiness of data

## Participants

Ten participants: five experts, including two University professors in the area of disability, a director of a DS Association, a Director of community relations of a DS Association, and a partnership for people with disabilities, and five mothers (with a child with DS age 23 and older) who were willing to be interviewed participated in the study.

## Study design and analysis

First, a pilot study took place by interviewing experts and mothers to get feedback on the questions and if any change was needed. The

outcome was that according to experts, services at school are different from after school and that some students with DS may stay at school until the age of 21 or 22. Therefore, it was decided to interview mothers who had an adult with DS age 23 and older. Second, data collected in two parts: In Part 1, experts were interviewed and collected data was analysed. In part 2, mothers were interviewed, and part 2 data was analysed. Later, an analysis was conducted of part 1 and 2 combined. Interviews were analysed using content analysis. Fortune et al. [11] states computer software is not always necessary for doing qualitative research. Computer software requires that the researcher be very knowledgeable about the analytic methods and procedures they use. Furthermore, it does not automatically reduce research bias, nor improve the reliability or credibility of the analysis (Ibid). Ethical approval for this study was provided by George Mason University Institutional Review Board Office (IRB Net ID: 1166035-1) and participants provided informed consent to participating in this study.

### Instruments

Theorizing rather than theory testing reflects the dynamic way that researchers interact with ideas and interpretations during analysis. Theorizing allows for conceptualizing without necessarily producing a theory- the reality for the vast majority of qualitative studies [2]. There is no theory testing in this study and it is based on three open-ended questions which assisted in understanding and describing the quality of life of adults with DS.

Questions for experts are as following:

1. How adequate are service programs for adult with DS in Virginia, in the following areas: Health, Rehabilitation, Education, Employment, and Nutrition
2. What are the unmet needs for adults with DS in the following areas: Health, Education, Rehabilitation, Employment, Nutrition
3. Is there anything else that you would like to mention?

Questions for mothers are as following:

1. How adequate were service programs that you have received for your child in the following areas: Health, Rehabilitation, Education, Employment and Nutrition.
2. What are unmet needs for your child in the following areas: Health, Rehabilitation, Education, Employment, and Nutrition.
3. Is there anything else that you would like to mention?

### Findings

Findings are presented in two parts: part 1 is related to experts' interviews, and part 2 is related to mothers' interviews. Each part was categorized according to the sections of the interview. The findings from this study provide valuable information for social workers and health professionals working with adults with DS.

#### Findings of part 1

The most important points which a majority of participants mentioned are summarized as the following eleven sections:

#### Health

One of the problems is that dental care is covered until the age 21 and after that it is not free. All parents have an insurance program, and

some have also a private insurance which they pay less money for medical costs.

Participant No. 2 says: There is an insurance called Medicaid for people who are eligible (low income people) but there is a waiting list, so not all can get it, especially people with a disability, people of colour and non- English speakers have little access to it, or if they have it they get little service. Sometimes a social worker or a special teacher is not aware of it. But, according to Virginia law if an individual with a disability is in a serious condition, she/he will get \$700 monthly but must have a social security number which is a gate to pass for getting services. Finding doctors who are willing to see adults with DS on a primary care basis is a problem.

Participant No. 3 says: For example, there is a 20-year-old with DS who still goes to a paediatrician because they cannot find a doctor. Or some people move in (to Virginia) for example, a mother of a 25-year-old with DS asks where she can find a doctor. That is a difficulty with DS. In Northern Virginia, doctors are not willing to see adults with DS. Parents can find a paediatrician, but they can't find a doctor who is comfortable treating someone who is not young. Usually, parents use insurance and get dental care through school. When it comes to insurance companies, either the insurance company pays, or parents pay. The access is there, the battle is who is going to pay for it. Many of our students are qualified for Medicaid which is something that helps them. Many medical service providers do not receive adequate training about Down syndrome (or most other disabilities) and often don't know where to refer children who need specialized care or assistance from social services.

#### Rehabilitation

It is under health and is available in school such as speech therapy. There is a real cut off when the child leaves the school. In school they get all services, and after school they try to get services and there are different parents. Sometimes, there are parents who get good services for their children and are not happy but, there are parents who do not get good services but are happy. It goes back to parents' expectations and a child's condition. People are on Medicaid but if there is no provider it is no good to you. Services are good at school but when they get out of school at age 22, parents should seek for services. Virginia has a fairly typical vocational rehabilitation system compared with other states.

#### Education

According to Federal law, all children including children with a disability should attend school at most until the age 21. Some can get a school degree, and some can't, but to get social skills. Some also go to a vocational center. There is a battle with the education system if they stay in normal classroom, later they go to resource room. As the children get older, they spend more time in the resource room and it prevents them from taking general classes. In middle school, they are mostly in the resource room. Some special teachers say: okay, children with a disability can have gym with other peers and there is a battle between parents and school. It is not shocking if a fifth grader still goes to first grade. Normally, they get a certificate the same year that their peers graduated. They go to school until the age of 22. In Fairfax County there are centres like David Center, and they do more job training. I know a girl with DS who could get a diploma from high school and went to NOVA community college for two years and got her associate degree in May 2017. Then she transferred to George

Mason University in Sep.2017 and will get a university degree. There are some who go to Mason Life.

The adequacy of educational services is somewhat variable depending on what part of the state a person is in. In suburban counties in Northern Virginia and Richmond, special education is typically good, but in rural or less affluent areas the services can be poor. There are wait lists for early intervention services in some parts of the state. Supports to help a child transition from school to workplace/higher education are not as adequate, and I think there have been efforts to improve transition services.

## Employment

There is a waiting list, therefore they sometimes have difficulty finding a job, usually they find a job in a restaurant, or cleaning, or packing papers and they are paid less money.

Participant No.2 mentions: It is right that according to the law 3% of people with a disability must be employed but if the person is eligible. Usually people with mild disability have a better chance of getting a job, for example: a person who has a limp or has an appearance deformity. If they can find a job they are paid less than \$2 per hour, while the minimum is \$9 per hour. There is job training, but it is temporary. It is difficult to get a job.

Participant No.3 says: The biggest issue plays more on employment. The fact is that the paper industry is gone. There were jobs such as using paper, filing, putting things in newspaper, organizing paper, and in the mail room. Now there is email and how automation is changing jobs. So, there are some jobs for people with disabilities. The good news is that adults with DS can read, do math, and they also use the computer, which wasn't the case 30 years ago. Now they have more opportunities for a job. In the past, when you got a college degree you had a good job. Now with the same degree you are a receptionist. So, parents pay for the program in Mason Life in order for their children to get a degree, but their children find fewer jobs. In Virginia it is not a law to employ people with disabilities but, there are government programs such as Source America which is a major employment for individuals with a disability.

Participant No.4 says: The biggest issue is getting a job and to stay in the job. Many times they get a job and do good work but their boss leaves and somebody else comes in. We have Metro access which is free. Another big issue is travelling to and from the employment. Usually it is \$4 a ride which is \$8 a day. Metro access is door to door service, so pick them up from the house and get them to work and bring them back. The biggest thing for us is training our people and gets them a placement that appreciates their skills and understands that they need other support especially with new tasks. That's a challenge.

Participant No.5 remarked: Employment supports are a huge need. Competitive employment or supported employment services are expanding, but slowly. As a result, employment outcomes for people with developmental disabilities are poor. Many people with developmental disabilities spend their days either at home or at habitation centres. Nationally and in Virginia, improving employment outcomes is one of the biggest areas for improvement, and has received considerable attention in recent years.

## Nutrition

There is no program by government, only there are sometimes food stamps.

Some adults with DS are not active, and because many have access to TV, video games, I Pads, and instead they are sitting at home getting very little exercise. Americans eat poorly already. It is hard to say them to go and run. They ask with whom? How? There is a good Olympic program here, but adults with DS are not active there.

Our folks with DS no doubt are more sedentary and they do not feel full, so both of those things are potentials for obesity.

Adults with Intellectual Developmental Disability (IDD) including Down syndrome do not have adequate nutrition. Obesity, hypertension, and diabetes are quite common. A big part of the problem is economic. Many parents of adults with people with disabilities can't afford healthy food, so they end up eating cheaper frozen food or fast food. For people who live in group homes or other forms of congregate care, the problem is sometimes even worse. Service reimbursement rates for residential service providers are typically not enough to allow them to purchase fresh, healthy foods and staff often does not have skills to cook that food (or help people with disabilities cook it). Access to exercise facilities is also expensive, making it hard for many people with IDD to get the exercise needed to be healthy.

Regarding Unmet needs, there are five sections, and the most important points are as following:

## Unmet needs regarding health

Parents are responsible for medical costs. Medicaid does not cover everything, and they do not have it after school (age 21), therefore they need to ask for it. Insurance system needs to be better than the present situation. Services are not the same in all states. For example, New York State has better services than Virginia. We need to make doctors more comfortable to see adults with DS, and yet they have fears to treat individuals with DS. That is in general, worldwide we need more research on DS. Now individuals with DS live longer lives. There may be adults with DS who are also with autism. We should have more doctors to see them. Doctors do not have enough information about DS. Participant No. 3 says: There are also doctors who make generalization about DS when they were interns or residents and give wrong information to mothers who are going to have a child with DS. For example, still in 2017, they say your child would not be able to read or to write and you should take your child to an institution.

According to Brown et al. [5] medical practitioners historically have assumed that people with intellectual and developmental disabilities are unlikely to improve greatly. That is one of the major reasons why previously people were put into institutions and in many places this view still prevails. So, it is important not to close the door on change.

Funding is the first important issue. Participant No.3 continues to say: We have ridiculous funding. Something happened with us within the nation. A few months ago, in a congressional hearing, one of the doctors said, they allocate \$2000 for HIV as where they allocate \$100 for DS. It is a ridiculous proportion. Doctors are willing to do research, but they ask who is going to fund it. I hope we can improve this situation for doctors.

Certainly, training for healthcare providers about DS could be much better. Health care transitions (moving from paediatric care to adult



care) have been an issue of concern for years. Healthcare access remains a challenge, especially for specialized treatments (for example services for individuals with high behavioural support needs). Often, Medicaid pays for more comprehensive health and behavioural health supports than private insurance, meaning that many people with DS and their families have significant out-of-pocket healthcare costs.

### **Unmet needs regarding rehabilitation**

When adults with DS reach 22 years of age, it is difficult to find services. When you get things like Service Source, there is a major problem to get services, like a Medicaid waiver where a waiting list is 10000-12000 people long in Virginia. There is a huge gap. This should be one of our priorities. If an adult with DS is sitting and waiting for services nothing happens, only if parents get sick and are unable to take care of their adults with DS or if they pass away there is a possibility to get funding. Adults with DS get off school at 22 when they are at home for a long time waiting, their education, and therapy deteriorates. In Fairfax County after school they would continue to get medical training, even though it has been changed. We do have people sitting and waiting for some funding to get services.

Many people with DS would need a higher level of support (and more long-term support) than vocational rehab would generally pay for and that may leave some individuals with DS without enough support.

### **Unmet needs regarding education**

People with a disability can register in Mason Life Program but they only take a few easy courses and get no university degree and parents must pay tuition for four years, but they have free bus services. Rich kids go to college, poor kids go to work.

Participant No.5 noted that transition services could be improved quite a bit. While schools do fairly well integrating kids with DS in academic parts of school, social integration is still lacking. There is quite a bit of research to indicate that people with developmental disabilities, including DS, have few friends, do relatively little in the community, and others feel lonely. Intellectual Disability Education Act (IDEA) only really covers core school activities, not the social aspects of school, so I think supporting the social development of kids with DS is an area of unmet need.

### **Unmet needs regarding employment**

The problem is in a long waiting list and blue-collar jobs with less money.

Participant No.3 remarked: "Now with a new movement there is a saying that: we don't like that people with a disability get lower pay than others which is against human rights. Some jobs are shelter work shops where they hide people with a disability to do the work. The movement says they should not be hidden they should work side by side. If there is more of that there is potentially less and less jobs for individuals with disabilities and I think it is dangerous to our community."

This idea is supported by Butterworth et.al (2015) who states that "segregated workplaces are widespread, and little progress has been made toward expanding integrated employment opportunities in the community" (p.164). Parents may be among the most powerful forces shaping the employment-related experiences and outcomes of their daughters and sons with intellectual and developmental disabilities

(IDD). The force of families has long been recognized by the inclusion of parent involvement as a basic principle of Individuals with Disabilities Education Improvement Act [12].

Participant No.3 continues: "We do not train the employers, so, I see that as an issue. You know people with DS make a good relationship and if the boss leaves, they might feel who do they go to and you could see how that situation make them get easily fired. In addition, in Northern Virginia there is good transportation but in other areas there is not. Developing supported employment is a major unmet need not only in Virginia but nationally. I think work needs to be done on multiple levels... government programs could do more to promote and pay for supported employment, people with DS need more efficient programs to help them gain work skills, and employers need incentives to hire workers with DS. In addition, I think we could do much more to support people with DS in higher education. There are a few programs around the country to help people with developmental disabilities in higher education, but I think we could do more."

### **Unmet needs regarding nutrition**

The problem of obesity is common. One participant noted: There is lacking in Virginia. We try to address, first, we eat horribly in America. There is a tendency for people not to eat healthy. There was sort of an explosion of them in the early 2000s since nutrition and exercise for people with IDD were really hot topics around that time. However, I think some of the curricula failed to adequately account for the financial circumstances of people with IDD and their families and the barriers they face in obtaining fresh food.

### **Mentioned problems**

Answers to the third question showed that a main problem is shelter housing. Some of individuals with a disability prefer to live together because they are accepted in a group with other people with a disability. Participant No.2 mentioned that if they are in mainstream society, they are not 100% accepted by other people. I found out about it when I did a research with 60 people with a disability and, interviewed their families. They were between 20-30 years of age. Therefore, they should have the right to decide whom they would like to live with. The other problem is transportation. There is a CUE bus, but it has limitation such as coming in every half an hour weekdays and an hour on weekends. Recreation is also important.

### **Findings of part 2**

Findings of part 2 are categorized in 11 sections as following:

#### **Health**

Interviewing five mothers indicate that there is no problem from health perspective for their adult with DS. Participant No. 8 says that she could have good health services for her child due to her husband's job situation. Two participants said that their children had many health problems when they were very young but now they are in a more stable situation.

#### **Rehabilitation**

All adults had received service programs like speech or physical or occupational therapies, or infant stimulation program when they were young, and participants found these programs very useful. During

high school or after high school some of adults had other vocational programs.

### Education

The range of ages were 24, 27, 28, 28, 30 and all had finished high school, but they were in special classes where they did not have much chance to interact with other students, so in one case the mother chose a private school because she wanted that her child to be included in school activities. Participant No. 9 says: When she was in high school we had to put her in a private school for special learning challenges in tenth grade, she started ninth grade in public education. We found out the school really treated the kids in special education as little kids not as young people soon to be adults we finally yanked her out of public school. We forked over a whole lot of money for private school which was really worth it because she got to be included for the first time in after school activities, choir, basketball team even though she wasn't terribly good she still got to participate and be included, and yearbook club. Or, participant No.7 says we opted to home school our son to provide the one-on-one teaching he needed.

### Employment

From the employment perspective, participants are satisfied that their adults have a job except participant No.6 who is hoping to find a job for her child. Participants mentioned that the job is temporary and their children are paid less than other people with no disability.

Participant No.10 says: My daughter does have a part time job; she works three days a week. She just works in the morning like 7-10 at an elementary school like the younger kids. And they have a breakfast program for the younger children, so she helps with that and work 3 days a week at an elementary school. She's been working in it, this is the second year. She likes it a lot; I think it's exactly right for her.

### Nutrition

Regarding nutrition, participants do not mention specific programs. Only participant No. 8 says: This is an area that has been addressed in various individual programs within our larger support organizations. We attend when it is possible. Typically, these programs are provided through grants. My daughter has also attended Community Based Programs to learn more about nutrition (called: Weight Watchers). She paid a \$40 monthly fee for this.

Participant No. 9 says: Overall, nutrition is pretty good she just had blood labs and her numbers were very well, but I worry because she does tend to eat a lot of carbs and eats less fruits and vegetables than she should. That's something we're always working on with the group home and restaurant when we can.

### Unmet needs regarding health

Regarding unmet needs, on health services programs, participant No. 6 says her daughter's weight is the bigger issue, and participant No. 9 says: In terms of health I think right now the most important thing would be to get more exercise and be in some sort of exercise program with other people on a regular basis. And then make better choices for eating. I've talked to the group home about this and they do have some people in the home who need to lose weight to be healthier. They also have one person who needs to gain weight and is way too thin. They have a mixed group of residents. I think that's why they aren't able to help focus on those who need to lose weight. My husband and I have met with them at annual team meetings, and we've asked the job coach

at her job to help her make better choices. There's a need but I'm not sure how it's going to be met.

### Unmet needs regarding rehabilitation

From the rehabilitation perspective, participants had received good services for their children. One of the participants says: We may request PT to help our son develop a more typical heel-toe walking gait. Our question/concern is for long-term impact of his atypical gait.

### Unmet needs regarding education

Participant No.7 says: Our son continues to develop through various learning environments, including: Home studies; Young Life; on the job training, church and short-term classes. Participant No.8 likes to have more life-skill training for independent living.

Participant No.9 says: My daughter always had to be in a special education class. That was separated from the typically developing students. And she wouldn't have certain things. Like in elementary and middle school she would go to the library with other students that did not have disabilities and she would have lunch with them and field trips with them. For her day to day education it was a segregated classroom of just students receiving special education services. And I think that's a bad model because it denies the kids with special needs it denies them a really good education by a really good educator. And it also keeps them separate from the social life and all the other layers in their action and school environment. The only after school activity she was ever involved in in public school was kindergarten and first grade. She was allowed to be on a soccer team. After that she wasn't qualified for anything, any after school activities like Sports, music, math and nothing. She wasn't good enough; they didn't have a model to include her. She wasn't included in after school activities until tenth grade when we put her in private school. Then she got to do everything basketball team, yearbook committee, choir. That's how it should be; all kids with disabilities should be fully included in everything from the very beginning that way they're not, they're not looked down upon or feared by any other children. When kids with disabilities are mixed in with everyone else it's good for everybody. These students who don't have disabilities they'll understand that people with disabilities are just people like them. Right! Yeah! When they become the employers and managers of companies and stuff they'll know people with disabilities deserve a fair change. So, that you know is really a shame that a lot of school and school districts do not have that model of being really committed to including everybody. Of course, what that means is, for the students especially at the high school level in the intellectual disability classes, the really good students get by far the very best teachers. No doubt about it. That means kids with special needs they in our experience they had some pretty bad teachers in middle and high school. There's no excuse for that.

Participant No.10 says: I think it would be great if we still were in school sometimes because of regular routine and you stay motivated and you're on a scheduled and everything. I do think it's a shame that school ends at 22 at the latest. Here and there, like last summer she took part in a 2 week program called resources for independent living, because we don't work during the summer. She went to her old school; it wasn't affiliated with the school. They have classes for 2 weeks and learned about money and independent living and learned about job stuff. That was very helpful, but only 2 weeks. I wish there were more education opportunities like that like job training and independent living because most stops at high school.

### Unmet needs regarding employment

When adults with IDD work in a competitive work place they do not necessarily have reciprocal relationships with their colleagues [13], but too few have gainful employment. The lack of forward planning leaves our services in the position that when children with IDD become adults, find that they often cannot obtain employment and are sent to exclusive environments like training and sheltered workshop. The impact can be devastating as the sudden exclusion from their non-disabled peers and loss of social inclusion appears linked to a general deterioration which may lead to depression and in instances early dementia [14].

Participant No.10 says: I think it depends on finding a willing supervisor. I don't think every supervisor, like in her situation I think her boss is probably unique and willing to take on somebody with a disability. If something happened to her boss I don't know whether she would be given the opportunity. I worry, I do worry about that. She doesn't have like a contract for the job. She works depending on their budget for the year and the need, she doesn't have a contract. Every year I'm not sure she'll have another job right before the school year starts. It's kind of uncertain, I wish it were certain

### Unmet needs regarding nutrition

About a nutrition, participants No.8 says: A continuing education type of program for nutrition and healthy lifestyle activities with others in her social group would be a program we would attend. Participant No. 10 says: If there was a program for young people who needed to lose weight and do in a fun way like if it involved exercise, I would love to enrol my daughter in that.

### Mentioned problems

Participant No.7 says: Our son is blessed to have a very loving church family that not only accept him with his disability but share their lives with him and seek him out on a regular basis for fellowship.

We try and schedule a camp and or short-term Missions trip each summer for time away from home, fun, increased independence and service to others as part of his continued education and emotional and spiritual growth.

Participant No.8 says: We are a family who has been able to provide rich experiences for our daughter and are somewhat knowledgeable about resources for K. We don't always take advantage of these resources available to support our daughter because some processes seem very complicated. I learn about many options for K through my parent network. Again, the time it takes to sift through the options and processes, can be very complicated, especially, as we negotiate the usual work and family responsibilities. I'm not sure how to make this easier other than continue to initiate contact with organizations and be happy to make small bits of progress at a time.

Participant No.9 says: The other part of it is when a person turns 18 and is legally an adult; their parent no longer has any authority in terms of money or stuff like that. In other words the young person like my daughter, at 18, if she had gone out and say hanging with some friends and they decided to drink and they're underage and maybe they would tell her here's the money goes to a 7-11 and buy some beer. If she had done that and if that was you know she got in trouble with the law because of that, there's nothing her parents could do about it. When people with disabilities turn 18, it's important for the parents to talk with them and we need to have some way to help out, a support

for them legally. The options are like becoming your guardian or having you sign a power of attorney form that kind of thing. A lot of parents don't know about this. The thing about it is like my daughter we wanted to see if she could just sign a power of attorney form but the attorney we were working with said no she, I can't in good conscience let her sign a power of attorney because I don't think she understands what it means. Then we had to go to the guardianship route and that's very expensive. That cost us \$3000 to become my daughter guardian and that was with a discount, the guy gave us a discount for \$1000. Well, it's permanent. It's \$3000 to become her legal guardian and that will last forever unless we went to the court and said we think now we don't think we need to be her guardian she's doing fine. That would be a whole legal process you'd have to do through a legal process. She is always going to need some wiser older person or people helping her and being her guardian because she doesn't have a lot of common senses. I can't even let her cross the street alone she doesn't bother to look both ways. The concept of you're going to get hit by a car doesn't compute with her. Again, she has some really low levels of certain areas of life and very high levels in others. Below levels could really get a person in trouble.

Participant No.9 remarked: About our association I would like to say it's a very white, which is very sad to me mostly Caucasian. You know, our city is like 50 percentage black. So, we should have a lot more families, but they don't have the means, or they don't know, or they might not have transportation, their lives are probably full already and can't imagine how they fit in a meeting on the other side of town. Socially our group I don't think is very representative of the DS population in the greater metro area at all. I think, my guess is that would be true for every single group. You know there's such huge amount of families in the United States that if they're dealing with poverty then it has so many ramifications and it means that a lot of resources that they might be able to learn about and go after they don't have time. They might not even know there are resources like that. The medical people are not that proactive in educating their patients, but they should be, but they're not. Of course, there are a lot of kids who don't get primary medical care because of poverty. Our program we have clinics once a month, you know we just saw a child for some reason lost their Medicaid early on when they were one because I think mom didn't speak English and didn't know how to renew it and then this kid shows up at our clinic at 3 years old and hasn't been seen by a doctor since they're 1. That's not that unusual unfortunately. My daughter, she's an only child in my family. I only have two nephews, um who one has autism and the other one is pretty much on the autism spectrum. They're not going to be caregivers for her as they get older. We're not sure. That's one reason why we were very eager to make sure she got a Medicaid waiver so she could be in a group home so if my husband or I got hit by a car tomorrow, it would be awful for her, but she would have that community the people she lives with the staff there all the involvement she has in the community. She has a lot of circles of support informally around her. We've been very aware since she's been born, and we had a lot of miscarriages, so we were unable to have another child. We knew we are really going to have to plan for her future. That means having a will and it means getting her into a place where she would have people to live with and count on. It meant really pushing for the Medicaid waiver, so she could move in to the group home. It also meant setting up the special needs trust. So, once we're gone she'll have access to money even if she can't have more than \$2,000 in her checking account to be eligible for Medicaid. There are a lot of hoops for families to go through and a lot of pieces to learn about and there's no one place that spells it all out.



Parents remark that parent support groups are important for them. This is supported by Francis (2017) who states “participants indicated that promoting parent networks should be a professional ‘priority’ because ‘parents are hungry for parent-to-parent interaction.’ Participants made suggestions for facilitating such networks, including ‘connecting parents’ to existing parent support group, encouraging local parents to ‘get together and network [to] learn things from another parent with a similar problem,’ and creating local ‘mentoring program[s]’ consisting of parents ‘who know the ropes or would be a good fit to support another parent.’

Participant No.9 continues: The amount of services and education that a person with a developmental disability receives is still largely dependent on how hard their parents work. That’s one reason why it’s really important for parents to hook up with other parents or parent support groups so that they can have a community of other people who have gone through this and they don’t have to reinvent the wheel. You know one family at a time. Even if you get trained and really involved and good advocate and trained in advocacy. My daughter’s journey has still been unique and I’ve still had to fight at many junctures for her. It’s amazing. I’ve had very hard times. Disability rights they should be considered civil rights but they’re really not in this country unfortunately.

Participant No.10 says: I think some kind of extension of high school would be nice some kind of academic where you’re on a schedule. I’m not saying like school you go every day for 9 months but it would be nice to have some kinds of academics like 1 or 2 weeks out of the months so they have a schedule and continue to be motivated and learn. That includes job training, life skills. I think that kind of thing is always good.

She talks about getting married she’s had a boyfriend for a long time he also has DS. She talks about moving out and living with her friends. I don’t think she thinks about all that’s involved. When you get married you got to cook, clean, and wash clothes. I guess I’m guilty because I’m a stay at home mother I wash clothes, she can fix her meals, like sandwiches lunch and breakfast. I’ll worry about her using the stove. As far as other things like she can take a bath by herself. She needs help sometimes with washing her hair and with the temperature; she’s not always consistent with checking the temperature of the water. That’s the kind of stuff I still check the water before I tell her it’s okay. Just to make sure her hair is really clean I help her wash her hair, although when she’s at camp she pretty much does her hair. Maybe they check the water before she gets in. I really don’t think she could live on her own with just little supervision. I think she would need supervision.

Participant No. 10 continues: I do think about end of life a lot. I’m not sure what will happen. I worry about it because I do not have other children I know my daughter’s cousins would look after her. I don’t want somebody to feel that they have to take her in to their house, but I’d like her to be in a group home and monitored by a relative to ensure she’s well taken care of. We don’t have a waiver; we’ve been on the waiting list for 17 years. Right now things are up in the air as to where she would live if something would happen to us I do worry about that and think about that a lot. I think the fact that most things end at high school is concerning, some kinds of regular schooling routine or classes continued job training is helpful. I wish all these services didn’t stop at the end of high school. This waiver list is a huge concern because the way that is run there are not guarantees we’ll ever get one. It isn’t based on how long you’ve been on the list. People worry about the future because of the cost and having a safe place for your child to live when you’re no longer there to monitor them.

## Discussion

Findings indicate that the Virginia health care system could be improved. For example, finding a doctor who is willing to see adults with DS is a problem as there is a 20-year-old who still goes to a paediatrician. Dental care is covered until the age of 21 and after that finding a dentist is a problem. Medical service providers do not receive adequate training and still in 2017, some doctors say, your child would not be able to read or to write and you should take your child to an institution. This finding is supported by Dyke et al. [15] who stated that “mothers of young adults with Down syndrome described more difficult pathways to attaining stability in adult roles, environmental facilitators and barriers emerged in the area of support, relationships, services, systems, and policies”. There is a long waiting list for Medical Waiver which is a gate for getting services, especially people with a disability, people of colour and non-English speakers have little access to it, or if they do, they get limited services. Regarding rehabilitation, the majority of participants are satisfied with rehabilitation services.

Regarding employment, it is very difficult to find a job and if so, individuals with DS are paid less money. In addition, some jobs are shelter work shops where they hide people with a disability to do the work. Although there are numerous U.S. laws, agencies, and programs designed to increase employment for people with individualized support needs (ISN), unemployment is epidemic among this population [16]. People with ISN experience unemployment significantly more often than individuals without disabilities, despite marginal advancements over the years. The discouragingly high rates of unemployment for people with ISN can be attributed to numerous barriers including poor transition services, and negative employer attitudes [17]. About Nutrition, Americans do not have a habit of eating healthily. Individuals with DS have problems such as obesity, hypertension, and diabetes. A big problem is finance because many cannot afford healthy food. This problem is worse for those who are living in group homes because staffs do not have skills to cook that food or help residents to cook it.

Responses to the third question showed that the most important points are shelter housing, recreation programs, and limitations regarding CUE buses coming every half an hour on weekdays, and every one hour on weekends. It should be mentioned that a group of adults with DS who choose Mason Life usually use CUE busses. Adults with DS choose ordinary metro system or may choose a door to door system going to work. Therefore, changes are needed. Parmenter [18] argues that QOL cannot come about fully until there are major changes in social attitudes within the communities in which people with IDD and their families live. Turnbull [19] argues there is still a lack of understanding in society that people with IDD have to be treated and accepted in a dignified and equal manner. The first new item emerged is “acceptance”. Acceptance was an important point mentioned by four participants. If individuals with DS are not accepted they confront big problems such as spending time only in resource room when they are at school. They are hidden at work and are separated from the community. Accepting them in the church or other groups resulted in more inclusion and helped their social development. The second new item was when a person turns 18, she/he is legally as an adult. Their parents no longer have any authority in terms of money or stuff like that. If they go out and decide to drink and get in trouble with the law, parents cannot do anything about it. If parents have to go the guardianship route it will cost them at least \$4000 which they cannot afford it. This is a big problem for parents.



The third new item that emerged from this study is about marriage. A number of the participants expressed their children's interest in starting a new family. However, the concern is that married adults with DS who are currently on Medicaid Waiver will lose 50% of their income in case they opt for legal marriage [20]. The fourth new item mentioned by mothers is about the end of life for parents. Mothers are worried what will happen to their adult with DS after both parents pass away, especially when they are only children as mentioned by two mothers.

This section will be ended by a sentence from one of the participants who mentioned: Disability rights should be considered civil rights, but they are not really in this country, unfortunately.

### Limitations of the study

Quality of life may include different dimensions such as emotional well-being, personal development, interpersonal relations, social inclusion, and rights. Therefore, this study was limited to health, rehabilitation, education, employment, and nutrition.

### Further research and application

1. Participants noted the big gap between services during school years and after finishing high school. Future research is needed on how policy makers may fill this gap by allocating enough funding and implementing improved policies that address these concerns for adults with DS.
2. Professionals and mothers provided important insights into their perspectives on employment opportunities; future studies should explore the thoughts and experiences of fathers on this subject.
3. Future research is needed to collect data from families of colour and non-English speakers with an adult child with DS.

### Conclusion

From a service program perspective (health, rehabilitation, education, employment, nutrition), there is a discrepancy between provided services and unmet needs DS as following:

Allocated funding for adults with DS, which is low, \$100 compared to \$2000 for HIV programs in 2017 in Virginia and service programs presented to them, such as Medical Waiver with a waiting list of 12000 people and some had to wait 13 years or longer to have it, up-to-date information for doctors and parents, and more research on Down syndrome is needed. Parents' efforts to find services after school, such as dental services, finding a job for the child (adult with DS) on a long waiting list, nutrition problems which results in obesity, Hypertension, diabetes. However, there are adults who do not have these problems because they have Medicare Waiver and a job but, they are paid less money than others with no disability and some have shelter workshop where they are hidden which is against human rights, especially that their job is temporary. In addition, only a few have the chance to live in a group home. As well as families of colour and non-English speakers with a member with DS are involved less than white community. As a result, adults with DS are considered to have a low quality of life. It seems that adults with DS are marginalized once again.

1. The research has resulted in four new insights yet there remain many challenges:
2. Acceptance: Adults with DS want to be accepted in mainstream school, at work. In the other word it also relates to inclusion.

3. Marriage: some adults with DS think about marriage and would like to get married, but the problem is that in this case they lose 50% of their income if they are on Medicaid Waiver.
4. End of life: Parents are worried what would happen to their child after parents pass away.
5. The present law: When individuals with DS turn 18, they are legally considered independent people. However, they cannot make a final decision in every aspect of life due to not recognizing the legal consequences of their action. In addition, if parents decide to obtain guardianship, it would be a complicated process which costs them at least \$4000, as well as the burden of the required paperwork.

The emerging question is: Does quality of life of adults with DS in Virginia depend on their acceptance into society, marriage, solving employment problems or the law on guardianship?

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