

CLAUDIA JUNGHANS, ROB LAST

„Hey, I reached adulthood, now what?“

Adults who have CHARGE syndrome
talking about school, job, living and independence



CHARGE Syndrom e.V.

CHARGE Syndrome Association of Australasia Ltd

FOREWORD



We know a lot about CHARGE Syndrome but what do we know about the process of changing from one setting to another; from home to school, school to post school, home to living away from home?

CHARGE Syndrom e.V. (Germany) and the CHARGE Syndrome Association of Australasia (Australia and New Zealand) have collaborated to create this booklet focusing on some of the issues that arise in the adult years for people with CHARGE syndrome.



These can be the times when big changes occur, which can prove to be challenging, whether it be changing from home to school, school to employment or moving into independent or supported accommodation.

They require careful consideration, forward planning, supportive environments, collaboration and teamwork.

We decided to focus on the adults who have CHARGE Syndrome as we found there's not much information out there. We gathered the information from those who live it, from those who have CHARGE Syndrome.

The questions we asked came from the areas of school, job, living and independence. We wanted to hear about the school years, if they work and what kind of work they do, do they live at home or are they able to live away from home, and is that independently or with friends or is it in a supported living arrangement and what are their dreams for the future?

We also thought it was important to hear about the challenges in achieving these goals and to offer thoughts and ideas to parents on planning for these times.

We sent the questions to a range of adults, who have CHARGE syndrome, from all over the world. They came back with their responses, which is the basis for this booklet.

Some of the stories are written by themselves and some are written by their parents or in collaboration with their parents.

This booklet should give you a brief overview to show you the way it might be and also what it takes to get there.

We are very grateful to all those who participated and their parents. To Elke Ludwig for creating the publication, to Sandra Noorlander for the translations and editing support. And of course, for those who enabled this project through their generous sponsorship.

For us it has been a wonderful collaboration from the Northern Hemisphere to the Southern Hemisphere, via the wonders of technology.

Claudia Junghans
Rob Last AM



Claudia Junghans

1. President CHARGE Group Germany

Claudia is the first president of the German CHARGE family support group and mother of a 2004 born son with CHARGE syndrome. She, her husband and Julia Benstz (a mother with a girl with CHARGE syndrome) formed the CHARGE Syndrom e.V. in Germany in 2006. She regularly lectures on the CHARGE syndrome from the point of a view of an affected mother. She also heads the office of the German CHARGE group, organizes the German CHARGE conferences and edits the German Newsletter "Trommelwirbel".

Rob Last AM

Vice President CHARGE Syndrome Association of Australasia

Rob comes from an education background, specifically as a teacher of the deaf and as an Early Childhood Educator. He and a group of parents formed the CHARGE Syndrome Association of Australasia in the late 1980's. Since 1993 he has been a presenter at the USA conferences as well as the Australasian CHARGE syndrome conferences and since 2012 the German conferences. His most recent achievement has been as a participant in the „Understanding CHARGE Syndrome“ a free online course. He encourages anyone with an interest and/or an involvement in CHARGE syndrome to complete this course. It comes highly recommended.

Understanding CHARGE Syndrome – free online course
<https://understandingchargesyndrome.org/>

Offering quality education on the latest knowledge and research on CHARGE syndrome from the world's foremost experts in the field. It will significantly raise awareness of CHARGE syndrome amongst health and educational professionals and will strengthen the capacity of families and care givers in supporting individuals with CHARGE syndrome.

Belinda

37 YEARS



School

I went to a mainstream school for both primary and secondary. At school I received a one on one aid in the classroom for taking notes as I could not read the blackboard. I also had visiting teachers for blind and deaf students about once a week or fortnight. My main challenges at school were reading the blackboard. I also had orientation and mobility when I first started high school and when I did work experience. I also used a monocular to see the board.

I finished Year 12 and received my VCE. This is the Victorian College of Education, a certificate students receive on the satisfactory completion of their

secondary school education.

Before you finished school, what was your future plan for work and a place to live?

I'm not really sure what I wanted to do when I was at school.

Job

Whilst I was at school, I did work experience at a child care centre and at a I.T. place. I got orientation and mobility on how to get there. It was very helpful. I got my first paid job at 15 at a music store. The owner was nice to give me a job 1 hour a week to dust the shelves. I also worked at K-Mart from about age 17-20 part time.

Since leaving school, what are some of the things you have been doing, such as further training, paid or volunteer work, social and recreational activities etc.?

I have studied bachelor of Arts and am just returning to university to study Law. I have worked with Victoria Police doing administration work for 11 years. I've also done a lot of volunteer work with a legal centre and at the court.

I currently work full time for Victoria Police. I do administration type work on the computer. I use windows zoom to make the screen big. I now want to be a lawyer.

I did have job trainings from an employment service but found my current job and applied on my own.

Living

I live with my mother. I would like to move out into an apartment in the next few years closer to the city.

I want to live closer to the city because the public transport is better.



Independence

I am very independent with travelling and going to appointments and shopping. The things I need more help with, are cooking and household tasks such as cleaning.

I use a cane for awareness in busy places. And I use my mobile phone to enlarge signs and screens.

Other questions:

How do you stay in contact with friends and how do you access your community?

Just like most people. I go to the gym, stay in contact with people through phone/facebook.

Tell us about a typical week for you and what you like most.

I work full time and study part time online. I also try to go to the gym a few times during the week. I see friends sometimes on the weekend.

What have been the rewards since leaving school and what have been the challenges?

It was very hard to get my first full time job but I believe because I have one it will be easier in the future.

What are your dreams for the future?

I want to be a lawyer and help people. I want to live independently and be happy.



Ellen

37 YEARS



School

My first school was for students with physical disabilities. From there I went to a special support unit in a mainstream school.

I was supported by an itinerant teacher of vision, a teacher of hearing, a teacher and a teachers' aid.

The challenges for me were frequent hospitalisations, sometimes for quite long periods, therefore missing some of the curriculum which resulted in me

being behind the rest of the class and sometimes the teachers aid wouldn't turn up to support me in the class.

I finished year 12 achieving the Higher School Certificate (HSC).

Job

After leaving school I wanted to do floristry at a technical college, but this didn't work out because I am a wheelchair user and it was inconvenient for them.

I now work in supported employment, I do things like packaging and labelling. I also attend a life skills program three days a week. I work on goals and interact with friends and staff. I go to respite once a month and on every second Saturday I have a support worker to take me wherever I want to go.

I didn't receive any support in getting a job.

Living

I live at home with mum and our two cats.

My plan was always to live with mum. I want to continue to live at home with mum or with friends and a carer.

Independence

My iPhone helps me to hear better by connecting via Bluetooth.

I use Facebook messenger and Instagram a lot. I also text and email.

I go swimming once a week with my

day programme when other things are not stopping me.

A typical week for me is I go to my work packaging and labelling. Tuesday, Thursday and Friday I am at my life skills programme where I do exercises, budgeting and I work on my blog. On Thursdays I go swimming with a group of the clients and staff and Friday I usually go out. We go anywhere and everywhere. On the weekends, if I am not in respite, I have a carer once a fortnight to take me out on a Saturday to see friends, shop, whatever I want. The rest of the time I am with mum, we see family and friends and go to

different places. In the afternoons and evenings, I like to go on Facebook, talk to friends and read. I am also a part of the CHARGE Syndrome Association of Australasia. I enjoy this and plan meet ups with families in my area.

I enjoy all the things I do but the most challenging part is that a lot of my friends live far away so it's hard to see them often.

And for the future I want to keep doing what I am doing.



Sean

21 YEARS



Type of schools

I went to a mainstream local childcare centre and kindergarten before I started school.

I went to a mainstream primary school from prep to Grade 6.

I went to a mainstream high school from Year 7 to Year 9.

I went to a special school for three and a half years.

Supports

At primary school I had a full time aide called Lyndal. Lyndal could sign. Lyndal was with me all day every day. She always knew what was going on. She knew when I wasn't trying.

When I enrolled at the school, the principal added Auslan to the curriculum six months before I started. When I started some of the children knew sign language.

I had a visiting teacher for hearing impaired, called John. He came regularly during my early primary school years. He also was my visiting teacher at high school. He only came once or twice a term at high school.

I had a visiting teacher for vision impaired. He came every couple of months during primary school.

I had a physiotherapist called Kylie. She came to the school regularly to give me exercises to do. Kylie was my PT throughout my primary school years.

I had several occupational therapists visit me at primary school. The OT worked with the Physio to give me exercises to do.

I had several speech therapists visit me at primary school a couple of times a term and gave me exercises to do.

Lyndal my aide would be with me when the OT, physio or speech therapist visited me to learn the exercises and help me do them during my time at school. Kylie would draw pictures of the exercises and they also provided pictures and symbols to help me remember what to do.



In primary school I had a slant board, a laptop, Clearnote (a remote camera that could be focused on the blackboard and displayed on my laptop), FM system with speakers, a microphone, a lapel mic that the teacher wore and that helped me hear their voice better, a portable speaker to move to different classrooms. There was also a microphone that the other students used so I could hear their voices.

High school was harder than primary school. In high school, there was a separate learning centre for students with additional needs. I did not get much support in the classroom. I got more support in the learning centre that I went to once or twice a week for a few hours. The visiting teacher for hearing impaired visited me once a term. There was no Auslan support at high school.

Special school was much easier than high school. The special school provided lots of regular therapy support

with physios, OTs and speech therapists on staff. An onsite gym and pool for therapy sessions. Technology and equipment for my vision and hearing needs (FM system, visiting teacher of the vision impaired). The class size was smaller with more support workers in the classroom. I enjoyed going to school by bus with my friends everyday.

I finished Special School with Certificate II and II in Business (Victorian Certificate of Applied Learning).

Challenges

At primary school it was hard to keep well and out of hospital. I had lots of friends in primary school. In Year 6 I was co-school captain.

Sometimes it was hard to know who was talking in the classroom.

Sometimes I got tired during the day or had migraines.

In grade 6 I got a BAHA. My hearing improved a lot when I got it.

At high school, I went from small class sizes to 30 students in a class. I had to make my way to different classrooms carrying books and laptop. I did not have enough support in the classroom. I did not feel supported by the teachers in the classroom at high school. It was hard to keep friendships at high school.

At breaktimes it was hard to find friends because the playground was so big. Sometimes I stayed in the library. There were some kids I did not get along with. High school was tiring. I did not like high school, I did not want to go sometimes.

At special school, the curriculum did not really challenge me. There was not enough planning for transition to post school options. The hardest thing for me was being around other students with disabilities. I was always the only one with disabilities in a school until I went to a special school. I did not know how to be around people in wheelchairs. It did not take me long to make friends with my friend Connor who is in a wheelchair and non verbal. We are best of mates now. I learnt a lot about disability and our school helped have a Changing Places toilet facility put in our local shopping centre. I really enjoyed my time at the special school and I am still friends with the students in my group.

My future plan before finishing school

To run a test and tag business.

Work experience

The special school did not have a lot of luck getting work experience opportunities for me and my friends. I wanted to work at the local supermarket or hardware store or tool store but they would not give me a trial.

The school helped me get some work experience at the local Disability Support Coordination offices on the computer and Occupational Health & Safety (OH&S) checking.

I also trialled at a local factory packing donated fruit and vegetables but the work area was very noisy and I did not feel safe moving around the factory because the yellow lines were hard to see on the concrete.

I also trialled at a local factory where they took apart electrical items for recycling. I liked this job, but the company closed not long after I began. I later looked at doing work experience at another factory but they would not let me work in the recycling area pulling apart the items. I wanted to work there.

I did some volunteering at school helping the OH&S person check fire extinguishers around the school and make sure they had all the correct information.

My mum organised two days orientation at the local council. I got to see how the library works, how the council chamber works, how food safety works in city council, how the parking officers work.

Since leaving school

I left school in 2018. This year I have been going to woodworking for vision

impaired. I am learning to use machinery for woodworking. I am learning to use the machinery safely because I am vision impaired and my friends at woodworking are vision impaired too. I go there once a week and will finish in July 2020 having done three semesters. So far I have made chopping boards, jewellery box, tool box, coffee table, garden bench seat, and a TV cabinet. After I finish in July, I can go back once a week and do my own projects.

I go to gym twice week. Every now and then I also go on outings with some friends organised through a local day service that my friends and I from the special school are members of. I have been to a boys afternoon in the park and an art work shop. Next year, we will be doing cooking and going on a camp.

I would like to get a group together to do weekly swimming at the local pool. I would like to go to TAFE and do a furniture making course or a carpentry course.

Job

I do not have a job, but I do some jobs around the house to help. I put away the dishes and empty the dishwasher, empty rubbish and recycling, sweep floors, I do my own laundry and change my bedding.

I did some work experience in a factory. I enjoyed sorting parts, clearing

away tools, cleaning parts. The people were nice. I did two hours every fortnight for three months. I would like to work there again. Friends helped me get this job.

I would like to get some work in a hardware store or supermarket.



Living

I live at home with my mum and dad. I have a brother but he moved out a few years ago. In the future I would like to buy my own home. I would like to try and find one with a sizable garage for a workshop so I can do my own woodworking projects at home.

Independence

I began learning orientation and mobility in grade 3. My O&M teacher was called Darren and he understood my needs because he had colobomas just like me. He helped me learn to move

around the school safely and then we progressed to local streets and road crossings. O&M training slowed down at high school, but I started to do it again more regularly at special school. We learned to take buses and trains in our local area. I got to know the ticket system.

My family travelled on public transport a lot because we live near a station. Travelling on trains was familiar to me.

Woodworking workshop is situated on the other side of the city to where I live. I have to take a bus and two trains and walk about 1 km to the workshop. I get up at 5:30am to get there at 8:30am. I leave home at 6:45am and catch the 7:15am train. It takes about 45 minutes to get to the city. It is peak hour at that time. I change platforms in the city and catch another train. It takes 10mins to get to the last station and then I walk to the workshop. I know the safest place to cross the roads. I have to cross a very busy road but I make sure I use the safest crossing.

It took me 6 months to learn to travel independently to the workshop. I now travel there and back on my own every week. Sometimes, trains get cancelled or buses replace trains, but I know what to do now.

I use an ID cane when I travel on my own. I used to use the map app on my

mobile phone to check where I was, but I don't use it anymore because I know the route well. I always text my mother when I get on the train in the morning, when I arrive at woodwork and when I am leaving woodwork. I have my own house keys and can come home alone. Sometimes I text my dad to pick me up from the station.

I am independent with my tube feeding. I wash and clean my own feeding tubing regularly and make sure they are all working properly. I order my own consumables and formula. Every three months I email dietetics at the hospital and about 24 slabs get delivered a few days later and I organise them in the garage and in the cupboard inside when required. I also go to a bread shop near woodwork and buy some bread for my family.

I pick up my battery supplies from Australian Hearing.

I am learning to organise some of my medical appointments as I transition to adult care.

I am learning to travel to appointments by public transport.

When I did my work experience I practiced using an Uber. I booked the Uber and travelled there on my own twice. I had an orientation and mobility worker help me practice using the Uber until I felt comfortable.

I use the public transport app to check train and bus times. I have trialled

communication devices because my speech is not always clear, but I did not continue using it. If someone cannot understand me I either try saying again clearly or I write it down. It is quicker than a communication device. I don't think I want one now.

I have my own bank account. I use a bank debit card for purchases. I am learning to use this correctly and to check my bank account from time to time to make sure everything is OK. I have my own healthcare card, medicare card and proof of age card. I am learning to budget for things I want to buy.

I am tube fed and do not eat, but I like cooking. I also like making my own ice cream. Ice cream is the only food I like to eat. I can measure and mix the ingredients on my own. I can also help cook spaghetti Bolognese and banana and coconut bread.

I use a paper diary and a calendar to remember things and to know what we are doing each week.

Friends and Community

I stay in touch with family and friends on Facebook. It is easier to talk on Facebook than make phone call. Sometimes I do FaceTime with my friend Sophie. I also see friends from time to time at the social group. I like seeing friends, I also like being on my own.

I enjoy playing Lego, reading about trains and transport all around the

world, watching Better Homes and Gardens and reading caravan magazines and going to caravan shows.

I love woodworking and enjoy the people. I love making the projects and learning about the different tools and machinery. I want to work with wood and make things. My big dream is to work in the caravan industry and buy an old caravan and do it up myself. I'd also like to move out of home one day.



Michael 30 YEARS

School

What type of school did you go to – special or mainstream school? What supports did you receive at school? What was challenging for you at school?

The school was a school for hearing impaired children, with six children per class. There was one support person. I also attended the preschool class. The biggest challenge was that there were not only hearing-impaired children in the class, but also children with behavioral problems and so it was always quite loud.

Did you finish your education (up to Year 12 for example) and did you receive a qualification?

I completed 9 years of school.

Before you finished school, what was your future plan for work and a place to live?

My dream job was to work in an office.

Job

Did you do any work experience, volunteering or job training at school or when you left school?

What sort of work did you do?

What age did you start with it?

Did you need any help (assistance) in getting work experience or being in the workplace?

Internships were part of school, once at a DIY store.

Since leaving school, what are some of the things you have been doing, such as further training, paid or volunteer work, social and recreational activities etc.?

After school I was at a place where I was trained to be an office management assistant, I spent two years there. I didn't like it, because they didn't let me get any further, I wasn't suitable for an office, they said.

Then the Labor Market Service arranged a one-year vocational orientation course for me with several internships. Gardener (couldn't do it), another office apprenticeship (they didn't want me there), kitchen in a facility for disabled people (which I didn't want).

They always underestimated me as soon as I had introduced myself.

Then I got to do a course for office organisation that included ECDL (European Computer Driving Licence) etc.

Do you have a job, if so what do you do, if not what sort of work would you like to do?

I have had a 30-hour job at the Austrian Armed Forces for almost 10 years, in the Human Resources department. I like it very much there.

Did you or your family receive assistance to find a job?

We didn't really have any help until my mother wrote a letter to a minister who at the time also happened to be a teacher at my school. I wasn't in her class, but I knew of her.

My mother wrote down everything

that frustrated us, and the office manager of the minister got me my job. The head of the Human Resources department was a really great person who did not reduce me to my appearance and behavior.

Living

Where do you live now?

I have lived in a small apartment close to my mother since I was 18 years old.

Did you or your family receive assistance to find a place to live?

No, my mom found this apartment for me.

Where would you like to live in the future?

Still in my apartment.

Independence

What skills have you learned to become independent, for example shopping, travelling on public transport, medical appointments, household tasks, and how did you learn to do these things?

Actually, everything is working well, I need someone to come with me to doctor's appointments, I have someone who helps me with household chores or shopping. Sometimes I need someone to help me communicate.

What types of assistive technology or equipment do you use to be independent (for example an id cane, mobile phone, seeing eye dog, communication device, etc)?

What other things do you want to learn to help you be independent

(e.g. learning money skills, budgeting, cooking etc.)?

Mobile phone, laptop, I can handle money, not so much cook though - I prefer to go out for meals.

Other questions

How do you stay in contact with friends and how do you access your community?

For example, catching up with friends or going to see a movie together, or going to the gymnasium or swimming pool for exercise?

I have my leisure assistant who is also my friend, we attend football matches, go swimming, to aquafitness and postural fitness classes. I'm also on Facebook.

Tell us about a typical week for you and what you like most.

I go shopping on Monday, swimming on Tuesday, Wednesday too, fitness on Thursday, Friday, Saturday and Sunday for a match or ice hockey, I collect football jerseys, have about 700 of them. I write to the football clubs and they usually send me some of their stuff.

What have been the rewards since leaving school and what have been the challenges?

I am very happy that school is behind me, that was very good, and also since I have a job.

What are your dreams for the future?
I want everything to stay as it is right now.

Anna

31 YEARS



School

What type of school did you go to – special or mainstream school? What supports did you receive at school? What was challenging for you at school?

12 years special needs education and advisory centre with a focus on cognitive development (SBBZ CSG Föhrenbühl) and 4 years in a deafblind school (Heiligenbronn).

Did you finish your education (up to Year 12 for example) and did you receive a qualification? And for how many years did you go to school?

No, I received no qualification. I went to school for 16 years.

Before you finished school, what was your future plan for work and a place to live?

Work in a workshop for disabled people and live with my parents.

Job

Did you do any work experience, volunteering or job training at school or when you left school? What sort of work did you do?

What age did you start with it? Did you need any help (assistance) in getting work experience or being in the workplace?

Work experience in the context of vocational school in Heiligenbronn.

Since leaving school, what are some of the things you have been doing, such as further training, paid or volunteer work, social and recreational activities etc.?

Vocational training after school in Heiligenbronn for 2 years.

Do you have a job, if so what do you do, if not what sort of work would you like to do?

Yes, I work in a workshop for disabled people.

Did you or your family receive assistance to find a job?

No, we managed that all by ourselves.

Living

Where do you live now?

In a residential group of a sociotherapy facility.

If you live away from home what are your home arrangements; e.g. your own house or apartment, shared accommodation, supported living?

I live in a residential group.

Did you or your family receive assistance to find a place to live?

No.

Where would you like to live in the future?

I'm not able to answer that. I think at home is still the best. It's the place where people understand me best. But I also like to be in the residential group when the right staff members are there.



Independence

What skills have you learned to become independent, for example

shopping, travelling on public transport, medical appointments, household tasks, and how did you learn to do these things?

My parents are my legal guardians; they help me with the above-mentioned things. I can help in the household. I have always practiced different household activities with my mum.

What types of assistive technology or equipment do you use to be independent (for example an id cane, mobile phone, seeing eye dog, communication device, etc.)? What other things do you want to learn to help you be independent (e.g. learning money skills, budgeting, cooking etc.)?

I like cooking with assistance. With my pocket money I shop with assistance. I talk to my family via video chat. If the staff in my residential group were more familiar with the tablet, that would be great.

Other questions

How do you stay in contact with friends and how do you access your community? For example, catching up with friends or going to see a movie together, or going to the gymnasium or swimming pool for exercise?

I have only few friends, but that doesn't bother me. I like the young staff at the residential home and at

work (I also like older staff, if they treat me with appreciation). I like my family best, my sisters. I have 3 sisters, that is great! I like to look at my photo books alone, but also with other people.

Tell us about a typical week for you and what you like most.

Monday to Friday I go to work from 8:30 a.m. - 12:00 p.m., then there is lunch in the residential group. In the afternoon I often go for a walk with a guide, and then I go to work again for about an hour. On weekends I help in the kitchen, we take trips to different places. And every 4th weekend I can go home and see my family.

What have been the rewards since leaving school and what have been the challenges?

School was great, but now I'm grown up and I want to be treated like a grown up. I always enjoy being with people who communicate with me, understand me and have fun with me. I like going on holidays, especially to the sea. I like to visit my sisters and I am happy when someone in the family has a birthday.

It is difficult when I am not understood. I am quite smart, and often people probably think „she is disabled anyway“. My family takes great care that I can live autonomously as far as possible and that I am treated with respect.

What are your dreams for the future?

My wish is to have an understanding and orderly living environment, a job that satisfies me and people in my environment who appreciate me and support me accordingly, if necessary. This environment should give me so much security and „at home feelings“ that I will get along without my parents once that becomes necessary.



„Lebenshilfe“= German non-profit organization that offers work opportunities in sheltered workshops and support to disabled persons.

School

What type of school did you go to – special or mainstream school?

What supports did you receive at school? What was challenging for you at school?

Bianca attended a special school, a so-called G-school (a school for intellectually disabled children). On average, there were seven students in the class, one class teacher and one teaching assistant for caregiving tasks.

Bianca did not receive any additional support in her everyday school life, as there was no need for it.

Actually, Bianca did not experience any major challenges in her everyday school life. After it, was a school for children with intellectual and multiple physical disabilities.

They paid attention to Bianca's individual needs and impairments.

The CHARGE syndrome diagnosis was not yet known at that time.

They thought Bianca was suffering from autism and infantile brain damage.

Bianca

33 YEARS



Did you finish your education (up to Year 12 for example) and did you receive a qualification?

Bianca went to school for 13 years - including one extra year. She didn't graduate.

Before you finished school, what was your future plan for work and a place to live?

This is a decision Bianca was not able to make.

Job

Did you do any work experience, volunteering or job training at school or when you left school? What sort of work did you do? What age did you start with it? Did you need any help (assistance) in getting work experience or being in the workplace?

No, Bianca wasn't able to do something like that. The only thing they tried at school were handicrafts, such as sandpapering a piece of wood.

Since leaving school, what are some of the things you have been doing, such as further training, paid or volunteer work, social and recreational activities etc.?

Bianca hasn't done any of the things listed here.

Do you have a job, if so what do you do, if not what sort of work would you like to do?

After school Bianca moved on to the day activity center of a workshop for disabled people (WfbM).

Did you or your family receive assistance to find a job?

Basically, all of that happened automatically and without any problems. On the basis of expert medical opinions, the employment office along with the school and the parents concluded that Bianca would never be able to find employment in the labor market. This was why she switched

over to the day activity group at the "Lebenshilfe" workshop for disabled people.

Living

Where do you live now?

Bianca lives with her parents.

If you live away from home what are your home arrangements; e.g. your own house or apartment, shared accommodation, supported living?

These questions do not apply to us.

Where would you like to live in the future?

We as her parents would like Bianca to live in a place with residential groups in the future. Living on her own is not something we would consider for Bianca.

Independence

What skills have you learned to become independent, for example shopping, travelling on public transport, medical appointments, household tasks, and how did you learn to do these things?

Bianca is not independent in any of the above-mentioned areas. She needs constant support.

What types of assistive technology or equipment do you use to be independent (for example an id cane, mobile phone, seeing eye dog,

communication device, etc.)? What other things do you want to learn to help you be independent (e.g. learning money skills, budgeting, cooking etc.)?

Even with the aids listed here, an independent life would not be feasible.

Other questions

How do you stay in contact with friends and how do you access your community? For example, catching up with friends or going to see a movie together, or going to the gymnasium or swimming pool for exercise?

Bianca has no friendships. Get-togethers with former acquaintances from the workshop happen at the initiative of us parents. Outings such as visits to the Open House or Christmas market events at the workshop are handled by the parents without any assistance. The parents also book trips with the Lebenshilfe travel office. However, these trips have not resulted in any friendships or contacts.



Tell us about a typical week for you and what you like most.

Monday to Friday

7:00 a.m. Get up

Toilet/personal hygiene/get dressed/breakfast together at home.

8:00 a.m. Pick-up by transport provider, trip to Radeberg deaf-blind services for day activities (travel time approx. 10 minutes).

Upon arrival: Feel box, with different materials. Every day a different material, peas, lentils.

Depending on how she feels, little tasks such as:

- Weaving, stamping, tearing paper, papermaking
- Taking a walk in the botanical garden of the facility and/or
- Riding the exercise bike in the gym
- Perception exercises
- Singing bowls, weighted blanket etc.

Before lunch, depending on how she feels – midday nap in the music room

12:00-12:30 p.m. Lunch

12:30-1:30 p.m. Various activities, go for a walk

Employees record the events of the day on Bianca's talker.

1:45 p.m Pick-up by transport provider.

2:00 p.m Arrival at home
Break and cappuccino.

Go for a walk/rest, everyday family life, including shopping, gardening etc. We make a point of involving Bianca -> she is always with us.

Depending on the season, swimming in our own pool, swings, trampoline. Wintertime is more passive, as Bianca does not initiate activities on her own.

7:00 p.m. Dinner

8:00 p.m. Bianca asks to go to bed.
She listens to a CD or the radio before she falls asleep.



At the weekend

Regular family life with different activities, shopping, household, trips to the swimming pool, hiking, visits to the fairground with a Ferris wheel ride.

Sleep in and watch TV for some time, e.g. music shows.

What have been the rewards since leaving school and what have been the challenges?

Positive – Bianca was diagnosed with CHARGE syndrome when she was 23 years old. Ever since we have had access to information through the self-help group. And we have made so many new friends. Meeting friends from the CHARGE group has now become an important part of Bianca's leisure time.

After she left school, Bianca spent several years going to the day activity center of a "Lebenshilfe" workshop for disabled people. However, there she received only little support and encouragement there. They were not able to sufficiently respond to her needs as CHARGE was still unknown at the time, and even once she was diagnosed, they didn't have any staff with the relevant training.

Bianca often showed behavioural problems.

For two years now she has been going

to the day activity center of the deaf-blind facility. There, they very much strive to respond to her needs, and she has one-to-one support provided by students and gap-year volunteers. The residents at the facility are all older people (50+) and neither Bianca nor they can initiate social interaction.

What are your dreams for the future?

Bianca cannot share her dreams. Things she wishes for: anything that is fun, Ferris wheels, merry-go-rounds, cotton candy, fireworks, ice-cream etc. These types of wishes she does communicate.



Florian

30 YEARS



School

What type of school did you go to – special or mainstream school?

I attended a special school for the deaf and hearing impaired from 1996-2008. From 2008-2010 I went to a vocational training center in Mettmann.

What supports did you receive at school?

In primary school I had a super nice teacher - she did a lot of things with us and she knew sign language. Plus, she worked very closely with the parents and organized many meetings – even outside of work.

I do not really like to think about my

time at school - I often felt alone and I had few friends.

What was challenging for you at school?

I just don't like to remember and think about it. I think I felt alone, it was a lonely time.

Did you finish your education (up to Year 12 for example) and did you receive a qualification?

I could have - if I had made a great effort – completed 9 years at a mainstream school. Together, we thought about it and decided that a certificate from a special school might be better so I would have more support options after school.

Before you finished school, what was your future plan for work and a place to live?

My dream was to become a „film projectionist“. I was really, really into the cinema and movies. My class teacher took me to a big cinema in Düsseldorf and we asked for an internship. Unfortunately, that was not possible - because this profession will soon no longer exist – everything is digital nowadays.

Unfortunately, the career of my dreams was not a success.

Then I had to think again and did some internships.

At that time, I wanted to live in a shared

flat - as a first step away from home. This was something I was familiar with as my brother and sister also lived in a shared flat and I knew (in theory) how it worked.

Job

Did you do any work experience, volunteering or job training at school or when you left school? What sort of work did you do?

What age did you start with it? Did you need any help (assistance) in getting work experience or being in the workplace?

I twice did an internship in a toy store. Once at a bank. And once in a small kitchen, as kitchen help. Then I did an internship at REWE (a supermarket chain) - but unfortunately there was no possibility there either.

The last one I did was an internship in a canteen kitchen.

This was arranged and supervised in cooperation with the IFD (the labor agency's service for occupational integration) and the social worker at the Mettmann school.

The toy shop was great. It was fun. I stocked shelves, handled price tags and prepared order lists in the computer. Rosi was amazed how well I was able to do that. Unfortunately, I find arithmetic very difficult – so I couldn't work the cash register – which is why they could not hire me, unfortunately.

Sometimes I still visit Rosi and I like to think back to that time.

Since leaving school, what are some of the things you have been doing, such as further training, paid or volunteer work, social and recreational activities etc.?

I then went to the vocational training center in Mettmann for almost two years and that's when I did two internships in a retirement home's kitchen. With the second one I got hired by a canteen kitchen in Ratingen. There I had a wonderful boss with whom I got along so well – unfortunately, he has retired in the meantime. That was a big change for me. We understood each other „without any words“ and my concern was - how will I get along with the new boss and hopefully he will understand my way of communicating.

Phew - this change really cost me a lot of nerves. At first there were several misunderstandings and there were times when I no longer enjoyed my work.

We then again involved the IFD - I had come to know the woman quite well and since she herself is someone with hearing loss, she could completely understand me and my worries.

Then I had an idea - I wrote an e-mail to my boss - because I can write quite well - and explained my concerns to

him in this way - the next day we talked about it again and so we both got to know and understand each other better. Meanwhile we are getting along very well with each other - and if we ever get stuck - Marius (the other boss) helps. He always understands me and resolves some types of things for me.

Do you have a job, if so what do you do, if not what sort of work would you like to do?

Yes, I do. I'm a kitchen helper in the canteen kitchens at the Ratingen retirement home.

Did you or your family receive assistance to find a job?

Yes, we did. We worked very closely with the IFD in Düsseldorf and the Mettmann school social worker. And that helped a lot. With the help of funding, it finally became possible to set up a workstation for me – which is where I still work today.

Sometimes I get annoyed about having to get up so early - I start work at 6:00 a.m. - but I have a very nice team - sometimes we do silly things together and that's what matters.

Living

Where do you live now?

Assisted living apartment of my own.

As a first step away from home, I lived in a WG (assisted living group home). At first, everything went quite well -

but then we all didn't get along so well anymore. There were conflicts because of the common tasks everyone had to do and for me it was really hard to communicate.

When the only person with whom I really got along ended up moving out, I also didn't want to live there anymore. I wanted to get out of there as soon as possible. Together with my caregiver we thought about what we should do. My wish was to live alone and we thought about how that could and should work.

I was very lucky - Abdullah happened to know about a project in the same part of town. A place where people with disabilities live, who also have children and they have five apartments for individuals. He called the landlord right away - and one apartment was still available. We looked at it and had to decide within two days if we wanted to take the flat.

That means you have to decide: Can I manage on my own? How? What support will I need? Can I afford this? A mega-exciting time!

We decided to be brave and everybody believed in me!

If you live away from home what are your home arrangements; e.g. your own house or apartment, shared accommodation, supported living?

Did you or your family receive assistance to find a place to live?

We always did everything together.

My parents both work in the social sector and could fall back on a good network. And this came in really handy. With my current apartment it was Abdullah (the best caregiver I've had) who knew the landlord.

My brother has built me a great kitchen. He has hung the cupboards somewhat lower so I'm able to reach everything. He bought a washing machine that I'm able to operate - a stove where you can push in the knobs - so I can see directly whether the stove is on or off.

We bought and assembled my furniture together and everyone helped. I remember how proud and happy I was once everything was set up. It has become so cosy. And now I have a wonderful „nest“ to come home to from work.

Sometimes I do feel alone - but it's all better than in the shared flat.

Where would you like to live in the future?

With a girlfriend. ;)

Independence

What skills have you learned to become independent, for example shopping, travelling on public trans-

port, medical appointments, household tasks, and how did you learn to do these things?

I can do almost all these things thanks to my caregivers and my mother.

I can go shopping on my own. At the beginning of the week I write a shopping list of all the things I need. I think about what I want to cook during the week and then I go get it. Sometimes I go and stock up with the help of my caregiver - the rest I'm able to do alone in my neighbourhood. I cook for 2 days - so I don't have to think of something new every day.

Meanwhile I have learnt to do my laundry all on my own. If I am unsure, I ask my caregiver or parents or siblings. And if something ever breaks, it is very convenient to write to my brother and ask him what I should do. He is great at explaining how I can go



about doing something. Whenever he is in Düsseldorf for a visit and there is something that needs repairing, he always has time for me. I am very grateful to him for that.

I also buy my clothes on my own. I go to the city or order them on the Internet. If I'm not sure, I'll ask. My family and friends are good at giving advice for this. I'm allowed to do many things on my own - I ask my mom if there is still enough money in my account and then I start a shopping tour.

But I do not go to extremes and I know which bills have to be paid from my account (rent - electricity - telephone - housekeeping money...)

I make doctor's appointments together with my caregiver or my mother.

However, appointments such as with a hairdresser I do book by myself via an internet calendar.

I have learned most of what I need from my mother and my caregiver. My brother is also a great mentor.

After all, sometimes things need to be discussed that my mother or caregiver don't need to know about.

What types of assistive technology or equipment do you use to be independent (for example an id cane, mobile phone, seeing eye dog, communication device, etc.)? What other things do you want to learn

to help you be independent (e.g. learning money skills, budgeting, cooking etc.)?

My mobile phone is my most important means of communication and it gives me a sense of security.

It is great for directing questions at the people who are closest to me. They know how I think and what I mean with my words and they answer in a way that allows all of us to understand each other.

I would like to become even more independent - as far as it is possible. But actually, at the moment I am quite satisfied with everything that I have already learned.

My parents and friends give me a lot of freedom to try things out and they take me very seriously as I am.

Other questions

How do you stay in contact with friends and how do you access your community?

For example, catching up with friends or going to see a movie together, or going to the gymnasium or swimming pool for exercise?

Yes, but only a few. Mostly I'm in contact with them via WhatsApp. Sometimes I use a messenger.

Unfortunately, since my CI surgery I can't talk on the phone anymore. I think that's a great pity.

But I can hear again and I'm very happy about that.

So, I use WhatsApp/Threema and email.

I also meet with my friends. Unfortunately, my best friend (he also has CHARGE syndrome) does not live nearby. But we see each other as often as possible. And I always meet him at the annual get-togethers.

I would like to have more friends close by - but unfortunately it is not all that easy.

My caretaker and I are on the lookout for opportunities so this can happen.

Tell us about a typical week for you and what you like most.

At 4:30 a.m. my alarm clock rings.

I get ready and then I have a small cup of coffee.

At 5:30 a.m. my taxi takes me to work - I could also go on my own, however, there is no bus that could take me to work at this time of day.

At 6:00 a.m. my work starts in the kitchen of the retirement home.

At about 2:30 p.m. I get off. Then I take the bus home, on my own. Then it's time for a break.

Three days a week my caregiver from KoKoBe (advisory centre for people with intellectual and multiple disabilities) stops by to see me and we take care of things, go shopping or just chat. Sometimes we also do fun things together!

What have been the rewards since leaving school and what have been the challenges?

I was glad once I was away from school - the wrong friends, the wrong love and bad experiences.

What are your dreams for the future?

To travel and to discover new countries. New friends, including someone more than a pal, would be more than just nice to have, maybe a girlfriend and people that live close to me.

Where I would like to live later on - well, I haven't thought about it that much. I would prefer to stay in Düsseldorf. But I would love to travel to other countries - just definitely not live there.

I'd rather stay in Germany.



Niko

28 YEARS



“Lebenshilfe” = German non-profit organization that offers work opportunities in sheltered workshops and support to disabled persons.

Written by Niko and his mother

School

I went to following schools

2000 - 2009

„Hör-Sprach-Zentrum“ (Hearing-Speech-Center) in Neckargemünd. Bilingual project class for hearing impaired children with additional disabilities

2009 - 2010

“Lindenparkschule” in Heilbronn, department for hearing impaired people with additional intellectual disability (residential school accommodation)

2010 - 2014

“Paulinenpflege” Winnenden (residential school accommodation)
Vocational school level for hearing impaired people with additional intellectual disabilities.

2014 - 2016

“Stiftung St. Franziskus” in Heilbronn, department for the hearing and visually impaired with additional disabilities (residential school accommodation).

1st year vocational school level

2nd year vocational training department of workshop for people with disabilities

Support in school and biggest challenges

Hör-Sprach-Zentrum (Hearing-Speech-Center) Neckargemünd 2000 - 2009

Enrolment in a bilingual project class for hearing impaired children with additional disabilities, 5 pupils aged 8 years. The school project was funded and supervised by the Stuttgart Ministry of Culture during the first 4 school years.

A deaf teacher was hired, the lessons were bilingual, in sign language and spoken language. Twice a year a conference was held with the responsible representative of the ministry, school management, the teachers and the parents. At the end of this school project, the

class was divided into groups of less capable pupils, to which Niko belonged, and more capable pupils. Bilingual lessons were no longer held and over the years, the content of the lessons increasingly overwhelmed Niko.

Niko said: “9 years are finished. I don’t want to stay any longer.”

Problems in Neckargemünd

There is no separate department for intellectually disabled pupils at the Hör-Sprach-Zentrum (Hearing-Speech-Center). The few pupils with additional disabilities were isolated and very marginalized.

There was teasing and quarrelling. They wrote tests and although Niko had mastered the content in terms of signing, he could not even read the questions. He was frustrated that he could not show what he knew, e.g. by means of sign photos. They were not willing to enter into a cooperation with a school for intellectually disabled pupils.

Lindenparkschule Heilbronn 2009 - 2010

After several internships Niko decided to switch to Lindenparkschule in Heilbronn. There, they have a department for hearing-impaired people with additional intellectual disabilities, teachers and educators have a basic knowledge of sign language. It was already clear at the time of the transfer that only one more school year would be feasible

and that he should then switch to a place with a vocational school level. Right from the beginning, there was a sense of belonging with the fellow pupils with intellectual disabilities. Residential school was nice.

The classes focused on practical life skills and thus were easy to cope with, which also made the students feel proud of their success at school and self-confident.

Paulinenpflege Winnenden 2010 - 2014

Paulinenpflege, based in Winnenden, is a higher education facility offering vocational training to hearing-impaired people with an intellectual disability.

The school lessons were great fun. The teachers are competent in sign language and they teach practical life skills.

Accommodation in the residential school, however, was a big problem. Niko lived in a house with very independent flatmates who all communicated by means of spoken language. There were no joint activities – the idea was that boredom would result in motivation. This completely overwhelmed Niko and he became sadder and sadder - almost depressive.

When we voiced our concerns during conversations, they did not take us seriously. It was only when we wanted to switch school after two years that they offered to move Niko to a less capable living group. In this new group, he immediately felt comfortable and

made two friends. The teachers organized and managed the students' leisure time and activities.

When Niko's friends left the school, he too no longer wanted to stay in Winnenden.

Stiftung St. Franziskus, Schramberg-Heiligenbronn 2014 - 2016

The German CHARGE group had put us in touch with Stiftung St. Franziskus where Niko did an internship. He was able to complete another year of vocational school in Heiligenbronn. He was very happy at school, he enjoyed studying and he did, in fact, learn a lot.

The residential school group was very good, all the teachers and educators there are competent in signing.

For Niko it was clear that after finishing school he wanted to go back to live at home with his family and work for Lebenshilfe in the neighbouring village.

Problems in Schramberg-Heiligenbronn

Niko didn't make any friends in Heiligenbronn and due to the distance, he could only go home every two weeks.

Did you finish your education (up to Year 12 for example) and did you receive a qualification?

I didn't graduate.

I did 10 years of school and 5 years of vocational school.

My wish was to work in a sheltered employment program at Lebenshilfe

in Graben-Neudorf and to live at home with my family.

Vocational Experience

My Internships

Internship #1: during 8th grade (I was 16 years old) at the Lebenshilfe Graben-Neudorf in the assembly department.

My Mum had found me the internship with the help of my class teacher, who also came to see me at work during my internship. The people working at Lebenshilfe are not competent in sign language.

Internship #2: 2009 at Haslachmühle, Wilhelmsdorf (Haslachmühle is a facility for hearing impaired, multidisabled children and young adults near Ravensburg). Arranged by a former colleague of the class teacher in Neckargemünd. All employees at Haslachmühle are competent in signing. They have put together a set of signs of their own called "Schau doch meine Hände" (meaning = look at my hands).

Internship #3: 2012 internship at the age of 20 at Lebenshilfe Graben-Neudorf during the summer holidays on our own initiative, without assistance.

Internship #4: Internship in vocational training department of Paulinenpflege in Winnenden at the age of 21.

Internship #5: 2013 internship at workshop for disabled people in Backnang. Arranged by Paulinenpflege Winnenden. Some of the staff working there are sign competent.

Internship #6. and #7: Internship 2013 at a farm for people with disabilities in Winnenden. Organized by Paulinenpflege Winnenden. There are only a few employees there who are competent in signs.

Internship #8: 2013 internship in the vocational training department of Lebenshilfe, Bruchsal, during the holidays on our own initiative, without assistance.

Internship #9: 2015 individual days in the vocational training department of Lebenshilfe in Bruchsal as well as at a farm run by the Stiftung St. Franziskus in Heiligenbronn, arranged and supervised by the class teacher of the vocational school level. While at the farm, there was no one who was sign competent, some staff members of the workshop program knew sign language.

Internship #10: 2015 Internship at "Klabauterland", an indoor playground in Philippsburg, during the Christmas holidays. Arranged by the parents on their own initiative and with the agreement of the vocational school class teacher in Heiligenbronn. Without assistance.

During my time in vocational training at Lebenshilfe, I got to spend time in the following departments:

1. sewing
2. assembly
3. packaging
4. kitchen

This is what I did after school

4 years vocational school at Paulinenpflege Winnendenn.

1 year vocational school at Stiftung St. Franziskus, Schramberg-Heiligenbronn.

1 year vocational training department Stiftung St. Franziskus, Heiligenbronn.

15 months vocational training department at Lebenshilfe workshop for disabled people in Bruchsal (a sheltered employment program).

Job

Since December 2017 I have been working in a sheltered employment program at Lebenshilfe Bruchsal-Bretten e.V. in Graben-Neudorf.

I work ½ day in the kitchen and ½ day in packaging.

I love the work at Lebenshilfe, but I would also like to work at Klabauterland (the indoor playground).

I have made the decision to work at Lebenshilfe on my own. The social worker there said that they'll have me and she sent all the applications to the competent administrative office.

Living

I live with my parents.

My Mum is actively involved with an interest group called "Junges Wohnen" (Young Living). Its members, along with representatives from Lebenshilfe, gather information about new types of living arrangements for young people and also get in touch with investors.

In the spring I will be spending two weeks in an off-campus living group set

up by Lebenshilfe by way of a test run. What I would like best, is to continue living with my parents.

Once that's no longer possible, I would like to live in a shared flat where disabled and non-disabled people live together.

Maybe I will find a friend with whom I can share a place.

Independence

Shopping is okay but planning what I need is hard.

I have a shopping book with symbols and Velcro cards with pictures of food and other things.

At home I think about what to buy with Mum and then I Velcro the picture cards into the book. I can also use the book to ask someone if there is something I can't find.

I cannot (yet) use public transport.

I can't hear or read when there is a change in the timetable.

I cannot arrange and keep appointments with doctors, I'm not able to provide information about my condition. But I can show when I have pain, what the pain feels like and where the pain is.

I can do a lot of household chores - I learned this at residential school and in the kitchen at Lebenshilfe.

I cannot manage my budget on my own. I can get money from the ATM and also pick up my bank statements.

I use augmentative and alternative communication (AAC) when dealing

with hearing people.

I have

- a shopping book with symbols and Velcro cards
- a pharmacy book with symbols and Velcro cards
- a leisure book with symbols and Velcro cards
- an iPad with communication apps (GoTalkNow, MetaCom, Compass DE, Sign Dictionary and many more)
- an iPhone with WhatsApp so I can make video calls
- (new) a Smartwatch, so that I can feel when a call is coming in
- an emergency board with medical information and many other aids

Mum developed the shopping books with the help of experts from the AAC service.



Other questions

I have two friends.

I stay in touch with them via Whats-

App video calling and writing letters.

My friends live far away.

I visited my friend Andreas (he also has CHARGE Syndrome) at his residential living. We get to see each other at the CHARGE meetings. My friend Johannes comes for a visit 2-3 times a year. We play games, watch movies and go for walks. We laugh a lot together and just clown around.

My typical week

Monday - Friday:

7:10 a.m. the bus picks me up at home
8:10 a.m. start of work in packaging or in the kitchen

3:30 p.m. end of work

4:00 p.m. back home

Tuesday:

8:30 - 9:00 a.m. physical therapy at the sheltered workshop

Thursday:

8:00 - 8:30 a.m. physical therapy at the sheltered workshop

8:45 - 9:45 a.m. coaching lesson in reading and writing

Leisure time

Monday:

3:30 - 6:00 p.m. bowling, arranged by Lebenshilfe

Tuesday:

5:30 - 8:00 p.m. playing billiards with Noah (who is currently spending a gap year volunteering)

Wednesday:

4:00 - 5:00 p.m. health and fitness training, arranged by Lebenshilfe

Thursday:

5:00 - 10:00 p.m. cinema get-together, arranged by Lebenshilfe

Friday:

6:00 - 9:30 p.m. disco at Lebenshilfe

Saturday:

6:15 p.m. – midnight, a special get-together for friends at Lebenshilfe

Sunday:

3:00 - 6:00 p.m. weekly meeting for people using the talker in Karlsruhe with Mum.

At home I enjoy watching DVDs, playing games on my iPad or with my Mum and my big brother and his wife. Every day we go for a walk with our dog named Tabo.

The rewards since leaving school

I always liked the lessons in school. I enjoy learning to read, write and do arithmetic.

After school I didn't have to live in the residential school anymore – that was good. I was back at home with my parents, which I like best.

My dreams for the future

I would like to continue working at Lebenshilfe and live with my parents.

I want my colleagues to learn some sign language.

I would like to see my friends more often and I would like to go on holidays with my friend Johannes.

Maybe one day I will be able to get a job at the Klabauterland – the indoor playground.

Sarah

24 YEARS



School

I went to a mainstream school, most of my classes were in the learning support unit. I had a teacher aide for 15 hours a week. Reader/Writer for exams and extra time. What was challenging was studying, it was hard but I did it. Also fitting in, making friends and bullying was really challenging.

In New Zealand high school finishes year 13, which I did and got the qualification called NCEA level 3.

I live at home with my parents. I did think of working in Early Childhood / in a Kindergarten or preschool.

Jobs

I gained work experience at school in Early Childhood centre in year 12. I was 16. I needed help as I went to a family friend's kindy (she was head teacher).

I did volunteer work with Special Olympics which is to do with public speaking and competition admin (recording times, handing out ribbons). Training to be a Special Olympics Global Ambassador and doing my Equestrian training with Special Olympics. Box fit at the gym. Special Olympics competitions. I also do social things like social media, cafes, concerts, shows, CHARGE Conferences, travel overseas with family. In the future I would like to be an Instagram influencer.

Living

I live at home with mum and dad. In the future, I would like to live in a little house, a flat or an apartment.

Independence

I'm good at budgeting my finances. Using "Uber App".

Meals: baking cakes, making sandwiches, reheating meals and when dining out, ordering food and drinks.

Going to GP (General Practitioner) appointments, getting prescriptions from the pharmacy.

I learnt from Blind Foundation NZ - O&M (orientation & mobility service), my parents and my brother and a mo-

ney management course at school.

I also use ID cane, Smart watch and phone. 18+ card for ID. And I want to learn more cooking.

Friends

I love to drink hot chocolate at cafes or sit at local beach. I go to concerts or shows and cinema.

Access Community: I go shopping at the local supermarket, pharmacy, cafe, hairdressers etc. became a regular customer. Gym with trainer.

Typical week

Mornings:

Breakfast, clean teeth, inhalers (a device to deliver medicine to lungs), other medications, Fun Chi, Swallow Prompt (It is an App on my phone that helps me to manage my saliva. It provides a reminder to consciously swallow. I do a 5-minute exercise, so every 30 seconds it makes a beep noise that cues me to swallow. It reduces dribbling and aspiration of saliva.), Social Media.

Lunch:

hospital appointments or horseriding training or Special Olympics, paperwork or gym.

Dinner:

Watch one of my favourite TV show "Home and Away", long bath and more TV. Clean teeth, Medication and inhalers, social media and listening to music and bed.

I love horse riding, being well prepa-

red and organised and not having all my time occupied so not being "full on busy" and also being involved with my friends.

People asking me, where do you see yourself in 10 years time?

Do you want a boyfriend, why don't you get a job?

Trying to live my life with everyone giving their opinion on what I should do. Live somewhere which has good access to "Uber" and "Uber eats" (application on the iPhone, iPad or computer), cafe, restaurants.

I might retire from being a Special Olympics athlete. Go to the USA CHARGE Conferences, Europe CHARGE Conferences. Keep going to the Australia/NZ CHARGE conferences. Travel, take over my Great Aunt's apartment place in Rose Bay Sydney. Maybe have a little job.



Hannah 22 YEARS



School

Hannah started at a mainstream primary school for two years, then moved to a local special school from Years 2 to 5. In Year 6 her family moved house (from Oxford to Berkshire) to enable Hannah to move to a more appropriate special school. She stayed at this special day school in Berkshire for six years from Year 6 to Year 11. Hannah then moved to a residential special school in Kent for three years. When this school closed down suddenly in 2015 Hannah moved to her current residential special school/college in Manchester where she completed her

last year in school and then stayed on to do a college course. She is now in the last year of a three-year course at The Seashell Trust, a residential special college.

Hannah had a one-to-one support keyworker in class (although not always a trained MSI - Multi-Sensory Impaired intervenor) from Year 6 onwards. She has also had access to a quiet space where she can withdraw to when she is suffering from sensory overload.

Almost everything was challenging for Hannah at school. She has had to move school three times because the provision available was not sufficient to support her. The most obvious problems have been a lack of sensory integration therapy at an early age, a lack of MSI expertise amongst most teaching staff and being treated as 'PMLD' (Profound and Multiple Learning Difficulties) when her primary needs are related to MSI.

Hannah visited school up to age 19, then a 3-year college course to age 22. Hannah is working towards achieving an accredited Edexcel Certificate in Personal Progress which covers units such as 'Developing independent living skills (being healthy)' and 'Exploring Music'.

Hannah is in her last year of college. The future plan is for Hannah to move

in to a supported living arrangement closer to her parents' home in Berkshire (her college is 175 miles away in Manchester). It currently looks unlikely that Hannah will be able to do much in the way of supported employment.

Job

At her current college Hannah has had experience of recycling paper duties; restocking student's bathroom cupboards; and collecting milk for college from school each day. She has also undertaken paper shredding and laminating duties. At Wythenshawe Life Centre (Jan-July 2018) attended one



day per week and had responsibility for assisting with loading/unloading washing machines and tumble dryers; cleaning tables; litter picking and washing and drying pots. Hannah also has experience of house duties in her residential house which she shares with 3 other students, including shopping for both house and personal items; loading the dishwasher and changing and making her bed.

Hannah started working at the age of 18 – she needs constant supervision and encouragement for her work experience and volunteering activities.

Living

Hannah is at a residential special college (the Royal College Manchester, part of the Seashell Trust) in Cheshire. She is resident at Seashell for 45 weeks in the year, returning home for 7 one week breaks at home during the college holidays.

Hannah currently lives in a shared residential house at Seashell Trust with 3 other students. Her family is hoping that Hannah will move in to a shared supported living house when she leaves college in July 2020. For the future, Hannah would like to live in a shared supported living house, closer to home.

Independence

Hannah has been developing her independent living skills on her college course (e.g. shopping; household tasks), but still requires a lot of support with most activities.



in the community when she is staying at home.

Typical week and what Hannah like most

In a typical week Hannah would enjoy to go horse-riding and swimming, and also go on lots of trips out (e.g. in a mini-bus). Hannah also enjoys access to music / music therapy, and likes to visit (for a short time) a disco on a Wednesday evening.

Hannah enjoys food and would like to learn more about cooking.

Rewards and challenges

Hannah doesn't leave college until July 2020, but the challenge for her post-college will be to find enough activities and interests to keep her interested and happy. Her parents' dreams for Hannah's future are simply that she is safe and happy.



Assistive technology or equipment

In the last year Hannah has been introduced to a VOCA (Voice Output Communication Aid) by a Speech and Language Therapist at the Seashell Trust, although with limited success so far.

Friends

Hannah doesn't really have any friends, but has developed close bonds with respite carers who she has known for years and who take her out on trips

Completed on William's behalf by Frances Concannon (Mother)

William 21 YEARS



School/College & Job

William started at a mainstream Primary School with a Hearing Impaired unit and nursery. He attended the nursery from the age of approx. 2 to 5. He moved into the primary school and remained there for 3 years. Despite staff in the unit's best efforts his needs required more specialist provision. At the age of 7 we moved William to a Special School.

William remained at the Special School (Milestone Academy) from Year 3 to Year 14. He spent 3 years in the school's Post-16 provision, the last two of which were at a satellite site within the grounds of a mainstream Secondary School (Wilmington Academy). William sat no exams and left with no formal qualifications.

We believed William was still capable of developing his independence skills and continue to acquire knowledge. We hoped to find an appropriate College place for William to continue his education. William seemed happy to continue in a similar environment to school.

William is currently in his second year at West Kent College in his home town. He belongs to the Foundation Studies Dept and has 1:1 support from a team

of signing Communication Support Workers. He attends College 4 days a week from 9am – 3pm.

One day a week, at College, William has the opportunity to do a session of work experience. In his first year he helped in the College library. This year he has been offered the chance to work in the College café. He has only attended one session to date but staff report that he did well, clearing tables, re-stocking supplies etc and he seemed happy to be doing it. We think this is a really positive opportunity for William within the safe environment of

College, supported by staff who know him and can help him communicate with others and understand his role and responsibilities. College staff helped him secure this experience.

One day a week when not attending College, William spends time with his PA/carer. They regularly go swimming and eat at the café afterwards. William enjoys the swimming and is also confident with the routine. It is a great opportunity for William to use some of the skills he is learning at College, for



example, using money, self-care skills and mixing with others out and about in the community. We hope gradually to support William develop these independence skills further but understand that this will be a slow and gradual process.

William does not currently have a job. When asked recently about a job William was unable to answer. He may not have considered it and is unlikely to know what is possible. As his parents, we recognise the high levels of support that would be needed to allow William to access a job, however if that can be put in place we would like it if William could do something that he would take pleasure in and that would help him contribute to a community, for example working in a café (like at College).

Living

William lives at home with his family (Mother, Father and 17 yr old brother). He is happy here and has probably not even considered any alternative living arrangements. As his parents we hope, in time, to find a way to help William to live away from home – again with a high level of support – where he can experience an appropriate level of independence. We are working with Social Services to understand his needs and capacity with a view to finding such a place in the next few years.

Independence

William can use money for small cost transactions and is beginning to understand what to do if he does not have the exact amount of money. He can dress himself and is largely independent in his personal care, however he does need prompts to undertake some tasks and a level of supervision to ensure he has carried things out – for example getting up at a certain time on College days, going to bed, taking a bath or shower, washing his hair, cleaning his teeth. He can prepare simple snacks and meals for himself but may need prompts to do so. He can use the washing machine and dishwasher if asked to but again would probably need to be reminded that an overflowing laundry basket and no clean clothes means he needs to do some washing.

He is happy to help on a shopping trip and seems to understand the process of buying things. Once again we are uncertain if he could recognise when shopping (e.g. for food) is required and then able to plan menus, a shopping list and go shopping without significant support. He does not currently manage his own medical needs and appointments.

William learns and responds well to processes. He remembers the steps required to do a number of tasks. He has learnt these by watching us at home, by doing it himself and through the specialist education he has received

that has placed priority on acquiring “life skills”, over qualifications.



William is reliant on sign language. He therefore needs someone with him to assist his communication and understanding of the community around him. This has restricted to a large extent the opportunities he has had to act entirely independently – in reality he has never been truly unsupervised during his life. This is compounded by his ASD diagnosis and the anxiety and occasionally challenging behaviour he can present. This would pose a significant risk in busy or unfamiliar environments. He can become distressed and is not always able to cope with unexpected events.

William has a mobile phone. He likes to have it but sees it largely as a device to store games, photos or videos that he can access if he has leisure time. With assistance he can send text messages but has never shown any strong desire to do so without prompting. William has a computer at home on which he plays games (Minecraft, mainly), accesses the internet (to explore websites, look up things he like e.g. images of food or TV programmes). This is his favourite activity. He has a DVD player



and can load and watch films without support.

Living with his family William is involved in our activities - seeing extended family members and family friends etc. He has a good relationship with his PA and seems happy to spend time in his company. He will come to the cinema, loves to eat out at his favourite restaurants and never says no to a trip to a café for a snack and a drink. He enjoys going bowling and will go for walks. He likes to know what is happening from one day to the next, but rarely asks to do things himself, rather he waits for others to suggest or offer an activity. The only exception to this is when he wants to know what food will be on offer. He loves a takeaway at the weekend and usually knows whether he wants Chinese, Indian or fish and chips.

It is hard to know if William knows what greater independence is and if he would want it. He seems largely content with the life that he has at the moment. We believe, any changes and expansion of his independence will need to be introduced gradually and with great care, but it is something we are keen to facilitate.

A typical week

Monday

Woken up by mum, get up and dressed and have breakfast with support/encouragement from parents. Spend the

day with PA – going swimming, lunch after, perhaps a walk in the local park. Home again with PA to wait for parents to get home. Supper, time on PC, bed after 9pm.

Tuesday – Friday

As above but after breakfast wait for PA to arrive and then wait to go to College. College until 3pm and then home. Same evening routine as above.

Saturday & Sunday

Wakes independently, gets breakfast, plays on PC, gets dressed – may accompany Mum or dad out for food shopping or walk and café. Relax at home or go out with family if trip or activity is planned. Evening meal and

evening routine as weekday (esp. on a Sunday in readiness for week ahead). For quite a few years William has gone on holidays in the Summer organised by Sense. He also went on a number of school residential trips when he was younger. He really enjoys these trips and copes really well when away from the family if his communication, sensory and behaviour needs are understood and supported. He appears willing to try new activities and participates well in everything that is offered. Holiday volunteers and staff invariably comment on his engaging personality and sense of fun.



Jacob

31 YEARS



School

I went to Mainstream school. For the first seven years I was fully included in the general education classroom, even though I have severe disabilities/deafblindness. I had a one-on-one support person throughout, and a team of special educators (special ed. Teacher, speech teacher, hearing and vision consultants, state deafblind consultant, physical and occupational therapists) who met regularly with the general ed teacher to devise my program so that I was working on my goals within the general education classroom while simultaneously participating in class activities. For example, if my goal was to increase stamina for

standing and using my arms to reach, my job for a group project was to stand and hold the group's poster during the classroom presentation.

At Junior and Senior high school (age 12 and up) I was in a special education classroom, but still participated in some general education classes. My French teacher had me stamp and then cut out "Euro" rewards for students who received extra credit, and then pass them to students. This helped with my fine motor skills and social skills, as each student had to tell me how many they had earned, and then I gave them to them. It also helped the students to get to know and appreciate me as a member of the classroom.

In Senior high school I worked a great deal on vocational skills. My teacher set up outside work experiences for me. By the time I left school at age 26, (an age limit unique to Michigan in the U.S.—most leave at age 21) I was spending most of my school day out in the community working. I came back for lunch and to ride the bus to and from school. My transition after "graduation" was easy because I kept doing the same jobs.

Challenges included

Convincing the primary school that inclusion was a good idea. This took several years and finally we had a new administrator who changed the tone of

the building so that I was more accepted by teachers and students. It was quite a fight for my parents, but afterward, other students followed suit, and inclusion became more the norm in my school district. I am a pioneer!

Finding well-qualified and good one-to-one aids to work with me. Now in Michigan we have trained interveners, and if I was in school now, I would have had one with good training in deafblindness and a credential showing three years of training.

Having special education teachers who understood my needs. This was very difficult and didn't really happen until I was in high school (age 14), when I had a teacher for 12 years who took intervener training and learned all about deafblindness and PECs, my main communication system. I was extremely fortunate to have, for most of my school career, the same speech teacher, who saw me for several hours per week and advocated strongly for my needs with the whole team. For many years, she was my true main teacher, in my eyes. A challenge for me was the few years that they reassigned her and gave me someone new who really had no clue what to do with me. This happened three times, for a year each time, and she always came back. But those years were wasted.

Interestingly, because of the inclusive schooling I received in our small city in my early years, I had absolutely no trouble with friendships with the general education population. I par-

ticipated in cub scouts through sixth grade with a group of wonderful boys who assisted me to complete all criteria for achievements. In middle and high schools, students would often sit with me at lunch or give me high fives and fist bumps in the hallway between classes. At my graduating class' graduation commencement, at age 18 (I then went back to school for 8 years) when I walked across the stage, (although I really didn't understand the purpose of what we were doing), I received the loudest applause of any student graduating, out of over 400 students. I continue to be greeted by community members warmly as an adult because of my school inclusion.

<https://www.youtube.com/watch?v=uZ-CODAhIdCA>

I finished school with a certificate, but not a qualification.

My future plan for work and life was to live in my own home with full support and working in the community with support doing work that was suited for me or I enjoyed.

Job

I need one-on-one assistance in the workplace but am also able to do much of my work independently, with a few reminders to keep going. Beginning at age 16, my school team helped me to find and connect with these local businesses. The vocational training program at my school's district was

pretty worthless, and put people on crews, to pick up trash and do other such custodial work in groups. My own school team put together individualized options for me in my community, which helped me with my transition to work from school.

At school I explored many work options:

- Shredding documents at school, at our city’s recycling center and at the psychology department of the local university
- Pulling empty hangers off racks at the local used clothing store
- Wiping down menus, filling salt and pepper shakers, sweeping, watering plants, and dusting at a local 1950’s themed restaurant
- Sweeping and doing laundry at the local animal shelter
- Bagging dog biscuits at a local pet food store

I work at The Pixie, the 50’s diner, washing down menus three times per week. It is volunteer work, but at the end of each half-hour shift I go to the counter and ask for a strawberry shake and I am given one as my “payment.” This means much more to me as a reward than a paycheck, and works well because my guardian and the shop owner don’t have to deal with employment forms, payroll, and taxes, when I

don’t really need the money (I receive social security income provided for people with disabilities in the U.S.). I make and bag my own dog biscuits and sell them at local shops.

In Michigan, we have a ten-cent return for all soda and beer cans, etc. People accumulate these in great quantities because they are too valuable to throw away, but also many people cannot be bothered to return them. So, they pile up. I provide a service to people like this. I come to their homes/businesses and pick up their cans/bottles, and take them to the local shop to recycle them through large machines that read the UPC codes and spit out a receipt for money earned on them. I take the receipt to the front, feed it into the cash register machine, and receive the money. The money I earn from this and from the dog biscuits is donated entirely to the CHARGE Syndrome Foundation in the U.S. to help families who cannot afford to make it to the conferences. In four years I have raised almost a thousand dollars.

Did you or your family receive assistance to find a job?

Jobs contacts were begun at school, but dog biscuits and can return business (Entitled “Jacob Can”) were devised by my parents and caregivers. Work at the Pixie began through school, but because of a contact with the manager, whose son had played soccer and gone to school with my

brother. Community contacts have been huge in helping me achieve my current life.

Social/Recreational

I have a bike, a trampoline, and a hot tub at home, which I use a lot. I love to lie in the sun on my front lawn. I go swimming twice per week at the local university, visit the apartments of friends, and homes of my college-aged caregivers, take walks through the park during spring, summer and fall months, love the Halloween and fabric stores, looking at Christmas tree lights in the store, and walking all through the college campus and inside the buildings. People greet me wherever I go because they know me. I give high fives and fist bumps. My parents live next door, and we visit one another often.

Living

I live in a supported living with 24/7 supervision/intervener care. I have 14 college students at any one time working for me. There is a lot of turnover, as they graduate, and my parents put a lot of energy into hiring, but training happens quickly, and we learn to trust one another. I am really adaptable and don’t seem to have much problem with people coming and going. I recognize them and like some more than others. It’s hard for me when a bunch of new people are trained at once. I get frustrated at the need to keep “training

them” myself. However, my parents prefer this to having more consistency that would entail hiring people with less education and enthusiasm, and more burnout and entrenchment in the system.

Did you or your family receive assistance to find a place to live?

No. We approached the family of the elderly woman next door when she was 95 and in a nursing home and asked if they might consider selling her house to us once she passed.

Also in the future, I would not like to live somewhere else. I love my house!

Independence

I can do some shopping with my intervener independently, if directed to what to get off the shelf. I am pretty independent at my can return job, once at the store. I can dress and undress myself, eat by myself, and get around my house. I am able to make choices within my house without much assistance. For example, I will go into my room and put on my swim trunks and head out to the hot tub. I only need assistance taking the cover off and balancing to get in and out. I don’t need supervision in the hot tub or in my parents’ pool. Most of this I learned through repetition and slow withdrawal of supports over the years. Many of these things I just spontaneously started doing on my own.

I use a cochlear implant (Kanso) and an iPad for communication. My iPad has pictures on it I can use with a program called Proloquotogo. I use a picture schedule for my activities each day so I know what's going on, and I can make choices within that schedule for activities during my time off from work, although often I don't bother. I'm an adult and don't need to make a choice using a picture anymore. I just independently at home go and get what I want to do and do it.

I am always learning new things. It's never too late to gain skills. I am learning new signs all the time, with the assistance of my caregivers, who try to provide consistent signing with me. There are two things that my family would really like me to learn, which have been elusive so far:

- Use the toilet independently: we believe there's a neurological problem that prevents me from being able to tell when I need to urinate. I still have accidents sometimes, although this is getting better each year.
- Be able to tell my team/parents what is hurting when I am in pain. Some of my idiosyncratic behaviors often identify the existence of pain and what kind it is, but sometimes I am in pain and can not tell them where.

Typical week and what I like most

I love my hot tub and lying on my blanket outside. I love my baths in the evening. I do like routine and am happy to go and do my work most days (unless I'm not feeling well.) But I really like relaxing at home and in my room and on my window seat more than anything. Walking and balance take concentration and effort so any time I can lie down I will. My weekly routine includes two sections of work most days, with lunch and breaks in between them: Pixie/dog biscuits or Pixie/return cans, etc. I have Thursdays off because I work at the Pixie on Saturdays.

Rewards and challenges after leaving school

I have the life I want and the life that my parents envisioned for me on my behalf. I am happy with how it's going. The challenges have been the burden for my parents and include all kinds of agency and funding issues. For example, the agency tried to take away my nighttime funding a few years ago, insisting that I was safe by myself with a monitor with which I could ask for help by pushing a button and talking to someone. I am deaf, I don't talk. The state was trying to make cuts and save money. My parents sued the state and went all the way to federal court. The judge said the federal court was wrong and reinstated the nighttime funding and refunded my parents for money

spent for my care and all attorney fees. It was a huge precedent for the state, and many other people have benefited from it. Other things like that have happened in the last decade as well, as the financial crisis has trickled down to social services funds. Working with multiple agencies is like an extra part-time job for my mom. The paperwork and requirements are constantly changing, and it is difficult to keep up with compliance. However, my parents have made sure that this hasn't affected my care in any way, so I haven't felt the stress of it.

My dreams for the future

I am living my future!!! It would be nice if I could find one person to be with me throughout each day for the workday portion, for consistency. Perhaps a housewife or younger retired teacher who is looking for something meaningful to do...six hours per day for five days per week, who could manage the household more for my parents

and be consistent for several years so that my life was less dependent on the different personalities and methods of 14 people coming in and out all day. The college students could continue to be here for all leisure times, weekends, evenings, night-times, but I'd have consistency in a daytime/worktime intervener.



My parents worry about what will happen when they're gone, but guardianship and trust and will are all set. There is still worry in the backs of their minds that my home program will not be tended to as it is now, but they have a trusted party identified to keep it going, and my four brothers will help make sure things run well. One of my brothers is engaged to a former worker of mine, who loves me and will make sure I am okay along with my brothers and their partners.

Kristin

28 YEARS



School

What type of school did you go to – special or mainstream school? What supports did you receive at school?

I went to a Specialized School for the Deaf. Received all instruction in American Sign Language (ASL). Large print (16-pt minimum) and non-cluttered pages for materials.

Did you finish your education (up to Year 12 for example) and did you receive a qualification?

I did attend through 12th Grade and received a Certificate of Completion/Attendance (not a diploma).

Before you finished school, what was your future plan for work and a place to live?

My plan was to get a good job and maybe live in an apartment with a roommate.

Job

Did you do any work experience, volunteering or job training at school or when you left school?

I did two school years and one Summer in a School to Work Program. I did assembly jobs in a factory. I started at age 16. I had to have a Job Coach that could use American Sign Language to explain the job/work.

Since leaving school, what are some of the things you have been doing, such as further training, paid or volunteer work, social and recreational activities etc.?

I work in a Job Skills Training Workshop 1 ½ days a week. I started at 5 days a week, then went to 3 days a week. Now because I have a job, I only go to the workshop 1 ½ days every week. Most of my recreation time I spent walking in town, shopping, going to the library, chatting with friends on FaceTime or in Chat rooms.

Do you have a job?

I work 3 days at Jack's Donuts from 8am-11am. There I clean the kitchen, the restrooms, the lobby and the tables.

Did you or your family receive assistance to find a job?

We worked with the State Vocational Rehabilitation Services and we had several Case Managers and Job Coaches. But the last job coach found the BEST job!

Living

Where do you live now?

I live with my mom and her boyfriend in a house, though I wanted an apartment and roommate. But mom thinks I need to learn more before that can happen...or get better supports (from people other than my family).

Right now Mom is working on getting better supports from outside the family so that I can inherit the house and still live there with supports.

Where would you like to live in the future?

I LOVE my town...it's a close walk to everything! I want to stay in my house!

Independence

What skills have you learned to become independent and how did you learn to do these things?

I'm good at shopping in town. I use a dedicated public city bus (for people with disabilities) and a county bus service (door to door pickup/drop offs for work only). I'm working on transpor-

tation requests with both bus services (Mom's trying to help me learn this). I can clean the house OK. Mom transports me to all medical appointments. I'm still learning from Mom, and from the workshop. I also have a good friend (she can sign!) that does activities with me once a month (shopping, games at her home, visit parks, etc.).

What types of assistive technology or equipment do you use to be independent?

I have a cane (but don't use it once I'm familiar with the area). I use an iPad/tablet, smartphone, pen/paper. I need to learn more money skills. Mom set a spreadsheet in my phone and that helps me to keep track of money better and not overspend. I need to learn more about paying bills. (They are paid by „Representative Payee“ – i.e., from Federal Benefits, not from Mom's work pay.) I really want to learn to cook more. I use the microwave OK, but need to learn how to cook using the oven and the stovetop more ... and safely! I also need to learn more about how to schedule doctors and transportation to appointments (and request interpreters).

Other questions

How do you stay in contact with friends and how do you access your community?

Mostly use social media for friends. I chat a lot! I don't have many friends

available to go to movies or other things, and there are no people in our small town in the same age group that know ASL. I have some friends at the library. We play games and do other activities at the library. I walk all over our town and everyone knows me and says 'Hello'.

Tell us about a typical week for you and what you like most.

Monday, Tuesday and Thursday:

I sleep late! Watch TV or chat on Facebook with friends. I go to the library or shop and walk.

Wednesday:

I wake up at 6am; get ready for work; 7:30am the bus picks me up and I go to the workshop by 8:30am. I work (assembly/stuff bags/etc.) until 3pm. I have 30 minutes lunch at noon. Sometimes I go shopping or a group activity for part of day. I ride the bus home. Then I chill out!

Friday:

I wake up at 6am; get ready for work; 7:30am the bus picks me up and takes me to Jack's Donuts. I work (cleaning) until 11am, then the City bus picks me up and takes me to the workshop. I work until 3pm and ride the bus home.

Saturday and Sunday:

I wake up at 6am; get ready for work. Mom takes me to work at Jack's Donuts by 8am. Mom picks me up at 11am and I go home. Then I walk around

town, go to the library, go shopping. Chill and chat at home.

I Love, love, LOVE the job at Jack's! My boss is the BEST: He can sign a little!

What have been the rewards since leaving school and what have been the challenges?

Having no friends that live close is hard. No one to hang out with...only one friend once a month.

(Comment from her Mom: That is the problem when attending a State School...the students are from all over, and there may not be anyone the same age that lives close. Another problem when no one local knows sign language.)

What are your dreams for the future?

Keep working at Jack's Donuts. Live in my small town where people know me. I want to have a boyfriend some time... but maybe not yet. I want to find a friend that will sign (and drive!) and go places. Maybe get a roommate when Mom is not here anymore, but I want to stay in the house here.



School

Laura attended the public schools in San Francisco from preschool through Transition. She began school at age 3 and graduated from transition at age 22. She was always in a special day class in a regular or mainstream school at San Francisco Unified School District, which meant that she changed schools many times during her school career. Laura had a one on one aide for most of her school years. This was something that we had to work to convince the district she needed. Once the district realized her communication and orientation and mobility needs the district became more supportive of her need for a one on one aide. Laura also received Speech, Orientation and Mobility training, support from the California Deaf-Blind Services and for a while Physical Therapy.

A challenge during her school time was that the district never had a dedicated teacher of the deaf or a classroom that was mainly using sign language. Fortunately her Orientation and Mobility Teacher and her Vision Teacher used sign and helped train the rest of the team.

Laura was in school until she was 22, so she actually went beyond her preschool through 12th grade time with the district. She received a certificate but was not able to earn a GED (General Education Development Test).

Laura

34 YEARS



Laura's team had a plan for her future, which we began creating when she was in grammar school. She had some jobs that she could do videoed and her team came up with a Future Plan during a team meeting centred on planning for the future. The team discussed what Laura's future might look like if she could plan for and enjoy the things that were important in her life. We thought of activities she enjoys, what sort of community in which she might live, what supports she would need to enjoy her adult living and any needs or wants the team could

imagine for her. At the time Laura was in transition from school, we started working with the Arc San Francisco on a day program. Arc San Francisco is a learning and achievement center for adults with developmental disabilities. The Arc was also aware that we wanted supported living for her. Laura worked on moving to her day program at the Arc with her school team and two years after beginning her day program the Arc established a plan for her supported living.



Job

Laura has not done much 'work' since her chores at school. She does help with daily chores in her apartment and goes out with groups that may be involved in volunteer activities, but she does not 'work' per se. Laura has vision, cognitive, balance and physical challenges that make prolonged activity difficult for her and she has not shown interest in pursuing work according to the definition the world may use. Because of her mobility, balance and vision problems, she uses a wheelchair when she is out in the community.

She is able to get around her apartment and building quite well but the stress of a busy urban environment makes it difficult for her to get around out in the community without a wheelchair.

Laura has daily activities that she enjoys with her staff and friends and seems very happy in her present situation.

Living

Laura lives and has lived near 'Fisherman's Wharf' in San Francisco since 2009. Laura lives in a three bedroom apartment in the Arc Apartments operated by the Arc San Francisco.

Laura has a bedroom in a very pleasant three bedroom apartment that she shares with a roommate companion and another client of the Arc.

Laura has supported living through the



Arc San Francisco. Her family received assistance through the California Regional Center and the Arc San Francisco in finding a place for Laura.

Laura has a wonderful place to live where she is happy and hopefully she will reside there for many years to come. Laura always travels with staff. In her living situation she helps with tasks, which is part of her supported living plan.

She presently does not use assistive technology and her only assistive device is a wheelchair for going out in the community. Laura helps her staff with cooking and household tasks.

Friends

Laura has a great community in her apartment building and her friends come to visit her in her apartment. She goes into the community daily and participates in swimming, which is her favorite exercise.

Laura goes out with staff daily to activities in her area. She loves to go to the bay and the parks. She goes swimming with her family weekly.

Laura seems very happy in her living situation and has more community than she has ever had in her life. She enjoys where she is!

Our dream for the future is that Laura will enjoy good health and her community of friends in a wonderful living situation. Her family feels fortunate that Laura has been able to enjoy her living situation for a long time.



Malik

24 YEARS



His Best Life: A Young Man's Transition to Adulthood

Djenne-amal Morris - Malik's Mom

Transition is often thought of as a process in which young adults prepare for college or a career. For families of children with disabilities, it is a lifelong endeavor in which we support our children as they progress at their own pace to meet milestones most parents take for granted. It is a process that occurs in phases from the time a child is born.

When raising a child with special and complex needs, we are always preparing for the next skill to take them a step closer to independence. My son

Malik now lives in his own home, an accomplishment I once thought was beyond both of us. How would he live without my care? How could I let him go? Looking back at the journey we have had, I am amazed at how beautifully everything worked out. Is it perfect? No. But like most people, we strive for happiness and a meaningful life. And Malik is happy living his best life!

Malik-asante Lamar Morris came into our lives 13 months after his older sister Imani and 5 years before his little sister, Zakiya. His name means "The King we are thankful for who is destined to do great things." From the day of his birth he had severe medical complications. By the time he was a year old, he'd had four major surgeries, including open heart, esophageal, gastric, and testes surgeries, and over 20 hospitalizations for respiratory, viral, and gastric infections and failure to thrive. His daily routine seemed like a never-ending blur of g-tube feedings and visits from physical, occupational, and other early intervention therapists.



His blindness (functional vision in his right eye and light perception only in the left), from colobomas, was discovered at birth. He was diagnosed with bilateral profound deafness at a year old. We did not have a definitive diagnosis of CHARGE Syndrome until he was three years old. This was when he transitioned from early intervention at home to the Perkins School for the Blind deafblind preschool in Massachusetts, where his services were continued in an educational setting. He was given a 1:1 paraprofessional in the classroom and we hired people to assist him at home. Malik needed constant supervision by a medical professional. He could never be left unattended for fear of a sudden medical crisis. It became evident very early on that he would always need intensive medical care and 1:1 assistance.

We were fortunate to live near Perkins, so Malik was able to attend as a day student. When he was five, my husband, Michael, had a conversation with his teacher, Maura. They discussed the possibility of Malik being a border at Perkins someday. I was appalled as I listened to them. How could my fragile and medically dependent son live anywhere but under our care? I held up Malik and said, "Does he look like a border to you?" This would be the beginning of his nickname, "The Border." A joke of a name that would plot the path of his future. Who would have thought the journey to transition

would begin with a car ride in New England?

Malik remained a student at Perkins for six years. Later, he did become a border—not at Perkins, but at the Eastern North Carolina School for the Deaf (ENCSD). We moved from Massachusetts to North Carolina after Malik experienced a serious illness and his doctors recommended we live somewhere with less harsh weather conditions to give his body a chance to get healthier. Leaving Perkins was an extremely difficult decision. The rapport and trust built over the years with educators who had become like family was deep.

We enrolled Malik in ENCSD in 2015 as a residential student, when he was 9 years old. I thought my heart would stop the day we dropped him off. How could anyone take care of him better than us? Eventually, he got used to going to school Sunday through Friday and spending the weekends with us. He enjoyed this independence and looked forward to school. In fact, every Sunday when it was time to be driven back to school, he would get Dad's key and sign "car" and "go" repeatedly until they left. This was the beginning of fourteen years of Malik learning to become an independent young man, acquiring skills to take him into the next phase of his life. At ENCSD he was provided with two interveners. They were Deaf women—Krystal and Sheila—who

were certified to work with the deaf-blind population. They were his bridge to the world academically and socially and were instrumental in his integration into the community. We were able to build the same rapport and trust with his team at ENCSD as we had at Perkins. I became very involved in the school PTO, Board of Advisors, and providing support to other families over the years.



The year Malik turned 18 we celebrated his life, but with some trepidation in ways I had not felt with his older sister Imani. At age 18, he was chronologically a man, but still had significant needs that would require all of the services he had been receiving and resources to sustain them. We knew he was eligible to stay in school until he turned 21, but we grappled with how we could collaborate with his educational team to make the next three years meaningful so he would be able to live and possibly work in an integrated community of his choice.

We began planning how to help him fulfill his dreams and desires for the future. If it was work, so be it. If it was a circle of friends and new experiences, we were prepared to advocate for them all. Malik taught us, as he continues to teach us, that it may not be the future we had planned, but it is HIS future, the one that belongs only to him. He deserves the opportunity to live a fulfilling, meaningful, and happy life. Our role as his family at the time was to network and advocate for those things within the adult services world. A world that is based upon eligibility and not entitlement.

The next four years was spent gathering information to help Malik prepare for life after graduation. He stayed at ENCSD until he was 22. As with our other children, we hoped he would move out of the house after graduation and live his own life. But, how would this be possible? Who would take care of him?

My biggest fear was that the day after his June 7th graduation he would have to come home with some sort of day habilitation plan, with an endless juggling of habilitation workers coming and going and evenings of chasing him around after a hard day's work. Knowing how much Malik loved to return to school every Sunday, I knew he somehow desired continued independence. How could I help orchestrate conditions to allow him to live his best life?

His best life. As I said earlier, HIS life, not the life I had been planning for him for 18-plus years. Around that time, our family participated in a person-centered planning (PCP) session lead by a specialist from Eastern North Carolina University's deafblind program. This was an opportunity for Malik's village to come together in a joint effort to tease out his strengths, challenges, dreams, and hopes, and begin to develop a course of action towards independence. Malik could not communicate his future goals to us in a traditional manner, but the PCP provided a clearer picture of how to incorporate his desires into a plan for his future in his own words, so to speak. It enabled us to develop opportunities at school and home to enhance his skills related to work he enjoyed and identified the community of support he would need to achieve his goals.



Using this information, I began researching services that might be the best fit for Malik. I explored, interviewed, and visited hospital type settings, alternative family living homes, and group homes. We thought of building our own group home but were honestly too exhausted and lacked the resources to take on that challenge.

This was to be a very different experience than sending him to college. When I prepared to send Imani to college, we packed her up, took her to school, and trusted she would contact us when necessary. Malik's experience would be a different story. He was still vulnerable, medically and physically. There was also the slight concern that he might not understand this new transition and have adjustment challenges, and he did not have the capacity to contact me if there was a need.

He deserved to have a place to live where the staff was attentive 24 hours, where he could communicate in his language, learn independent living skills, make friends, work, be happy, and be surrounded by people who believed in him and pushed him to be his best. It wasn't about just finding him a placement; Malik needed a home.

In Spring 2017, we were presented with an opportunity to have Malik be part of a pioneer project. Darrin McNeil, owner of Serenity Therapeutic Services, Inc., opened a new

independent living home targeted to meet the needs of young men who are Deaf and have other disabilities. Malik was to be its first resident. The staff was both Deaf and hearing. Serenity also has a day program where he could go to advance his skills. This was the beginning of a dream come true. We finally had post-graduation plans for The Border! In fact, we decided to have Malik move into the house before graduation. Now we needed a transition plan.

For a month, Malik visited the home on weekends to get to know the staff. He brought things from home and school to help set up his room. In the meantime, we met with the staff to give them an overview of caring for a young adult with CHARGE syndrome and discussed Malik's plan and goals. On moving day, I felt a mix of emotions. I was excited and scared and had more questions than answers. How would he adjust to his new home? How would we as his parents adapt to the new world of adult services with a new set of professionals who were responsible for making the types of decisions that we had made for the past 22 years?

Transitioning to adult services was initially very challenging in several aspects. I had to establish a new team of medical professionals at UNC Hospital that served the adult population and understood how to treat a person with complex medical needs. We went

from doctors who had served Malik for the past 15 years to a cadre of new ones. This was a crucial detail because I would no longer be the primary person accompanying Malik to appointments. He would now be going to doctor and hospital visits with the Serenity staff, not me. In addition, it was necessary to educate and train a whole new staff on his medical and behavioral needs and nuances. Determining a collaborative medical protocol was of the utmost importance. I had to, once again, put my trust and my son in the hands of others.



Malik has lived on his own for the past year and a half now. He has thrived and is happy, living the life he was meant to live. A life so many of us didn't expect him to survive to see, yet alone one similar to the type of life all parents want for their children. When he

comes home to visit he makes sure his suitcase stays by the door as if to say, "This visit is only temporary. I have a home." He is the king of his castle and his roommates are his friends. He is learning skills and maturing. The people that work with Malik share how much they have learned from him and love him. The house manager told me, "Working with Malik has been an interesting experience. Despite having disabilities, he is extremely intelligent and highly capable of completing everyday tasks like cooking. Malik gets what he wants and is very affectionate with staff and other clients. It's truly a joy working with him."

The entire staff has been very receptive to learning about Malik, improving their skills and accepting input from me as a parent and professional in the field. It has become a true partnership in learning and building an environment where Malik and others can thrive. Darrin McNeil, the owner of Serenity recently told me that he is glad he took that leap of faith to open one of his homes to this population of young men, especially his buddy, Malik.

Malik has been my greatest teacher. He has opened my eyes to a world of possibilities rather than limitations. He's exceeded our expectations to live, thrive, and be independent. As I look back on Malik's life and our experiences with him, each transition has presented new challenges,

trepidations, and uncertainties about the future. But it has also been a wild, exciting roller coaster ride of laughter and love like none other, as well as a journey of growth in my personal knowledge and maturity, professional career, and capacity to support others. His life story has touched lives and inspired so many on a local, national, and international level. Malik has gone from the border to the student, to the young man living on his own, making a way in HIS world.



The article was provided courtesy of the National Center on Deaf-Blindness / NY / USA



Megan

27 YEARS



School

I attended a variety of schools. For Early Intervention and Pre-School I attended an out of district school for the Blind. I had a Teacher of the Visually Impaired and received OT, PT, Speech, Orientation and Mobility, Art Therapy and Music Therapy. I then attended an out of district special communication program for 2 years within a regular public school. Once my language took off at age 6, I was brought back to my school district in our regular elementary school. I was 2nd grade age but entered Kindergarten because I was behind academically and stayed in a regular classroom with a 1:1 aide from Kindergarten through 2nd grade. I was 2 years older than the kids in my class but that was ok. In 3rd grade I was placed in a smaller self-contained class

in my home school district with kids that had ADHD (although I did not) and mainstreamed for specialties like homeroom, art, music and gym. I still had my 1:1 aide. Things didn't go very well for me that year. I left my home district again and attended a variety of other special classes for children that needed behavioral supports over the next 6 years. By the time I was ready for high school, it was a challenge to find a placement for me. I then attended the Perkins School for the Blind's Deaf-Blind Program as a residential student till I turned 21 years old. I had speech therapy, occupational therapy, physical therapy, a Teacher of the Visually Impaired and a Teacher of the Deaf/Hard of Hearing, an Orientation and Mobility Instructor and School Psychologist while enrolled in all my schools. It was often challenging for me when there were outside noises and distractions and when I couldn't follow along in the classroom despite being in the front and center of the room. Background noise was always an issue and so were group discussions when I couldn't hear well. Sometimes my OCD got in the way of learning and I would lose my patience.

I completed my education at age 21 years old. I was hoping to receive a high school diploma but it didn't work out and I received an IEP (Individualized Education Plan) diploma.

Before I finished school, I worked with a Transition team to do personal future planning. I planned to return home

and live with my family and find part time employment and hoped to continue my education in a special college program.

Job

While I was at the Perkins School for Blind I was involved in their Work Study Program starting at age 15 and worked at various jobs with the support of a job coach. I volunteered in the Braille and Talking Book Library as a Library Inspector and had numerous supported employment experiences. I was a Weaver in the Perkins Caning Shop, a Greenhouse Laborer in the Perkins Greenhouse, a Merchandise Associate at the Perkins Student Store, an Office Assistant for NAPVI (National Association for Parents of Children with Visual Impairments), an Office Assistant for Perkins International and then held an off campus job as a Brand Attendant at Target.

When I left school, I held a short-term position as the Front Desk clerk at a Podiatrist's office with the support of the NY State Commission for the Blind. Once I had a state budget in place and was able to hire a Community Habilitation Staff person, I was able to attend a Special College Program for one year and currently continue in that program one day per week with a College Mentor. I have 2 steady volunteer jobs. I work at Afya – a non profit organization that collects and ships medical supplies to places in need – 3 times per week for 2 hours each time

and at another religious organization where I help with mailings and putting projects together for the religious school. I am recently employed part time through Supported Employment at our local Synagogue where I do Clerical jobs in the main office and get paid for my work. I belong to the JCC (Jewish Community Center) and work out and swim laps. I take drum lessons every week at a music store and belong to 3 recreational programs. Through these programs I attend weekly sessions of zumba, compete on a swim team and participate in Special Olympics 2 times per year and do a music program.

I attend monthly dances and play Challenger Basketball in the winter. I get together with friends when I am not busy. I still have doctor appointments and attend weekly speech therapy and behaviorist sessions.



I am happy to say that I currently have a paid part time job at my local Synagogue. I am familiar with the

surroundings and people and they also know me. I consider it my “dream job”. I work with an Employment Specialist through Supported Employment, but she will eventually back away and my Community Habilitation staff will continue to stay for support. I work 2 days per week for 2 hours at a time with the hopes of increasing my hours. I help with office work and uploading music sheets to electronic files for the Cantor.

We worked with a Supported Employment Agency and the Employment Specialist worked with me on a weekly basis to discuss my interests, update my resume and make a cover letter. Then we began the job search and found a job.

Living

I live at home with my parents. We have not yet looked into finding a place to live outside my family’s home. I would like to live in my own house/apartment, maybe with a roommate and 24/7 support staff. I would like to live near my family.

Independence

I’m independent at home but still need assistance with cutting and using the stove and oven. I can make my bed, pick out my own clothes, do my own ADLs, do laundry with minimal assistance, help set the table, do dishes and food prep. I learned a lot of independence skills while away at Perkins and also received some in home

experience through the Helen Keller National Center’s Community Support Program. I don’t travel alone, but I can shop and pay for my items and I do have a very good sense of direction. My parents still make my doctor appointments and take me, but I try to answer the doctor’s questions at the visit. My parents order my medications but I often go to the pharmacy to pick them up and pay for them.

I use an id cane for walking outside so people know I have vision loss. I have a hearing aid and a soft band BAHA to help me hear. I use a large iPhone and a large iPad to stay connected to people through social media sites. I would like to be able to travel using para transit.

Other Questions

I talk to some of my friends on the phone, I use Facebook to keep up with social media and sometimes I meet up with friends at my home or at an event or at a restaurant. I prefer to text or instant message because I don’t always hear too well by phone. And if there’s a problem with Facebook, I could get upset, so I limit my posts. My mom usually makes the arrangements to meet with a friend after she asks me. I access my community with support from my parents and my Comm Hab Staff worker and sometimes with help from my grandparents.

My typical week is busy. Every day is a different routine. My Comm Hab Staff person works with me Monday

through Friday from 9am – 5pm. My parents take me places in the evening. **On Mondays** I go to my paying job. I come home and have lunch, chill for a bit, take a walk and then go to my volunteer job. After dinner I go to my zumba class.

On Tuesdays I either go to the gym to work out or I go to my volunteer job if there is work for me. I come home, eat lunch and then meet with my college mentor at the library for 4 hours. I have an early dinner and then head to swim team.

On Wednesday I work, come home and eat lunch. I have some free time so I might be able to go to the gym or do my volunteer job. I have my Behaviorist in the afternoon and then I head to my drum lesson. I have my music program in the evening.

On Thursday I have water aerobics in the morning, head home for lunch and then I have my volunteer job in the afternoon. I have no evening activity and like to do scrapbooking or look at pictures.

On Friday I have speech therapy, then my volunteer job, lunch and have a free afternoon for visiting with friends, exercise, shopping or playing games. **Saturday**, I spend with my mom and we do water aerobics, go to a vegan restaurant (I have an egg allergy) and then pick up vegan bakery items at a coffee shop.

Sundays, my dad is home from work and we try to do family stuff and see my grandparents. I talk to my Grand-

ma on the phone 4 times a week. I try to practice my drums when the dogs are not home – they don’t like the noise. I like swimming and my college program the most.

Since leaving school I think my jobs have been very rewarding. It was very challenging for a couple of years after high school graduation before I had adult services in place and I was home a lot without a schedule. Now that I have adult services and I’m doing “self-direction”, I’m happy with all my activities.

Dreams for the future – I would like to live on my own someday and travel more independently. I think I would be very good at event planning and hope to have a job where I can use those skills. I would like to go out to my favorite restaurants with family and friends, attend services and events at my Synagogue, continue to go on ski trips and travel to Disney World and the beach. And of course, attend all the CHARGE conferences.



Steven

28 YEARS



My son Steven

by Valerie Muck

My son Steven was diagnosed with CHARGE syndrome at birth (it was just an "Association" in 1992!) Steven "came of age" in Ohio.

He was involved in a vocational training program (Project Search) and he had a comprehensive Individual Transition Plan. Transition while in Ohio was relatively easy, as there was sufficient interface between the

school district and the county. In addition to job placement and job coaching services, we also received transportation assistance.

In 2015, I transferred to the Pentagon. If you have moved a child with disabilities, you know the pressures of finding new doctors and support services.

As we no longer had the school district in our corner, we dealt directly with the county for adult services. Job placement? Nope. Job coaching? Nope. Transportation? Nope. There were lengthy waiting lists for all of the services we needed.

We eventually found my son a job volunteering at a thrift store about 8 miles from our house and, with no transportation assistance, we paid out-of-pocket for a taxi.

Last year we moved to Michigan. We've worked with the county and Michigan Rehabilitative Services to find my son meaningful employment. Job placement? Yes! Job coaching? Yes! Transportation assistance? Yes! Even though the services are available, it has still been a lengthy process and we have faced set-backs matching my son's skills and talents to long-term, meaningful employment. And transportation options within a relatively rural county are also challenging.

Every parent hopes their child will find competitive, integrated employment within their community. Parents also

want their child's compensation to be comparable to the compensation of a non-disabled worker performing the same tasks (including the same benefits and opportunities for advancement).

Nirvana, right? When nirvana isn't quite possible, there are organizations that provide non-competitive employment opportunities to individuals with disabilities. Two organizations I am familiar with, Production Services Unlimited (Southwest Ohio) and Work Skills Corporation (Livingston County Michigan) provide non-competitive employment opportunities within their distinctive 501(c)3 non-profit organizations.

Both organizations offer training that allows employees to develop job skills and soft skills. My son worked at Production Services Unlimited.

It was a very positive experience, and he was eventually placed in an enclave where he received minimum wage for part-time employment.

We recently contacted Work Skills Corporation as a potential option for my son now that we are in Michigan.

Some of our family's toughest challenges relate to employment opportunities. Our situation is a bit unique, as we've lived in three states since my son graduated from high school in 2014. Three states and three vastly different experiences.

Parents, caregivers and individuals

with CHARGE should research employment services within their community, county, and state.

It's never too early to start. Additional information about NDEAM can be found at:

www.whatcanyoudocampaign.org



IMPRESSUM

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In the context of self-help support according to German § 20 h Social Code Book V the brochure „Hey, I reached adulthood, now what?“ is financed by BARMER health insurance. Warranty or benefit claims against the health insurance funds cannot arise from this. CHARGE Syndrom e.V. is responsible for the content and the design.

BARMER

For more information on CHARGE syndrome these websites are full of helpful information.

AUSTRALIA
CHARGE Syndrome Association of Australasia Ltd
<https://www.chargesyndrome.org.au/>

BELGIUM
Belgian CHARGE Syndrome Website
<http://www.chargesyndroom.be/index.php>

FRANCE
Association CHARGE
<http://www.associationcharge.fr/>

GERMANY
CHARGE Syndrome German
<http://www.charge-syndrom.de/>

ITALY
Mondo CHARGE
<https://mondocharge.it/>

THE NETHERLANDS
Dutch CHARGE Syndrome Network
<https://www.chargesyndroom.nl/>

SPAIN
Asociación Española Síndrome de CHARGE
<https://sindromecharge.es/>

UNITED KINGDOM
The CHARGE Family Support Group UK
<http://www.chargesyndrome.org.uk/>

USA
CHARGE Syndrome Foundation
<https://www.chargesyndrome.org/>

