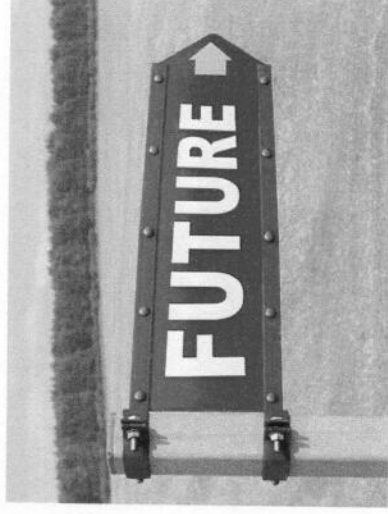


Essential Advice for Parents for Right Now & The Future



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WELCOME

Please introduce yourself and tell us in a few sentences about you and your family member.

Agenda

- Who are the experts?
- Why is creating a life plan important?
- What is a life plan?
- Doing exercises about your loved on
- Alternatives to guardianship/supported decision making

Experts

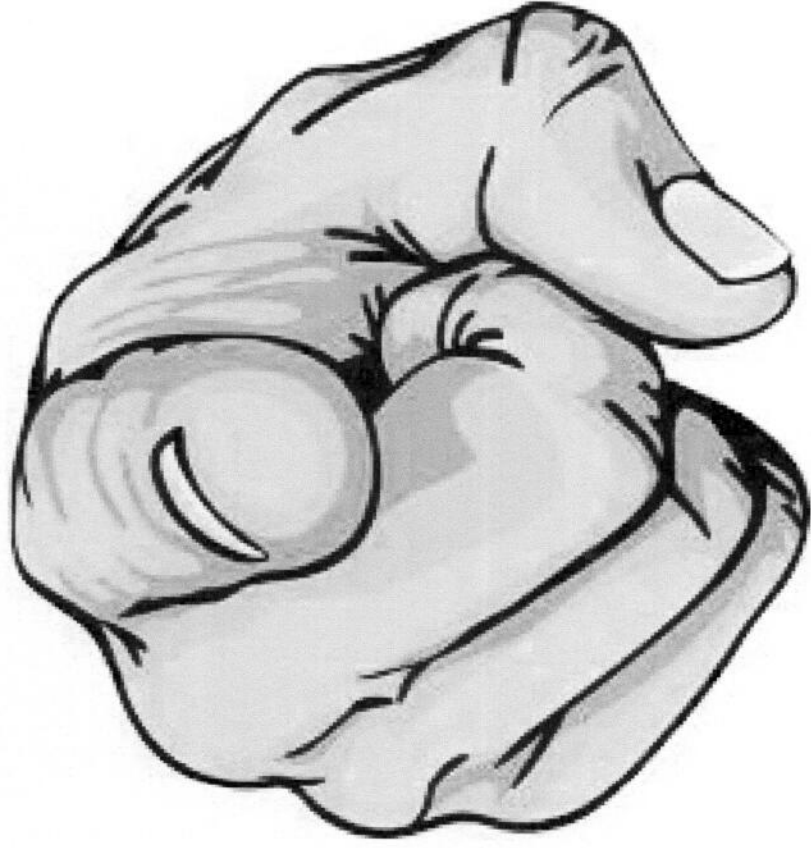
Who are the experts that are in your child's life?

Expert



some
An expert through
experience knowledge
extensive knowledge
called in for advice

YOU!



Why is developing a life plan important?

- A snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow;
- A way of organizing and communicating what is important to an individual;
- A way to see information clearly to help with decision making;
- A way to begin to develop a letter of intent

What is an Essential Lifestyle Plan (ELP)?

- ELP is a guided process for learning how someone wants to live and for developing a plan to help make it happen. It's also:
- A flexible process that can be used in combination with other person centered techniques;
- A way of making sure that the person is heard, regardless of the severity of disability.
- Essential Lifestyles Plans are developed through a process of asking and listening. The best essential lifestyle plans reflect the balance between competing desires, needs, choice and safety.

My Own Plan

Mandy's Plan

Date of the 1st plan

2/25/09

Dates the plan was changed

5/29/09, 11/22/10 5/27/11

What do I hope that this plan will help me accomplish?

I am a young woman who is currently living in an apartment in Queens with the support of my mom. I participate in the Self Determination program and manage my own budget and services with the help of my circle of support. I am hoping that this plan will paint a picture of who I am as a person and how I hope to be supported.



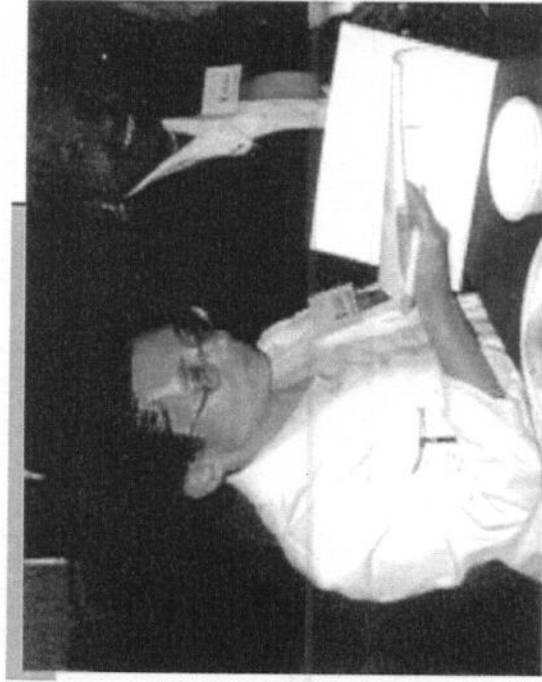
My Own Plan

My Introduction - Great Things About Me

What do people like and admire about me? What are the good things they say about me? How would I like to be introduced?

- My personality!
- Pretty and Stylish (Big Hazel Eyes!)
- I dress very professionally for work.
- Great Work Ethic
- Hard Worker
- Reliable - Always on Time!
- Dependable
- Good Attention to Detail
- Organized
- Helpful
- Calm, cool and collected
- Accomplished - Has won many awards, achieved many goals and has been recognized for various achievements.
- Pioneer - Paved the road for others with her work with self determination and supported employment
- Kind and gentle
- Good self confidence
- Funny & Witty
- Keen observer
- Great memory
- Caring
- Logical
- Moral/ethical
- Values family
- Perseverant
- Courageous
- I am not afraid to try new things, but sometimes need help to find new things!

New Things I Have Learned About Myself



My Own Plan

What is Important to Me

What do I want other people to know about the things that are important to me? Who are the people that are most important to me? What do I do with them? What are the things that I have to do (and things I need to have) if I am going to be happy?

<ul style="list-style-type: none">• Be a member of my community
<ul style="list-style-type: none">• Work - Have a paying job & be in an environment that is kind and gentle with office work responsibilities
<ul style="list-style-type: none">• Be around my family or speak to them over the phone regularly
<ul style="list-style-type: none">• Feel good and have less headaches
<ul style="list-style-type: none">• Have my day, be my way - have control over what I do
<ul style="list-style-type: none">• Not be rushed, let me take my time
<ul style="list-style-type: none">• Be recognized for my achievements by being acknowledged for a job well done
<ul style="list-style-type: none">• Sometimes need help adapting to a world which accommodates taller people
<ul style="list-style-type: none">• Be able to do things my own way (cooking/taking care of my body/health)
<ul style="list-style-type: none">• I am healthy - I eat well and don't smoke.
<ul style="list-style-type: none">• Pay bills when I receive them
<ul style="list-style-type: none">• To be able to attend all of my activities

New Things I Have Learned About Myself



My Own Plan

What are the characteristics of people who support me best?

If I was going to pick a new person to work with me (e.g. case manager, staff in a home) what would I look for? What do the people that I like to work with have in common? Have there been people that I couldn't work with? What do they have in common?

<ul style="list-style-type: none"> • Friendly/Personable <ul style="list-style-type: none"> - someone who speaks to me about themselves and makes me feel comfortable • Good sense of humor - make me laugh and I will make you laugh in return! Lets have fun together • Patient - I do things in my time, hang in there with me. • Reliable (do what you promise, be on time, call if you can't) Please don't make promises that you can't keep. • Consistent • Smart • Creative - think of new things that I can experience in life. I have done many things but would like someone to share new ideas! • Be enthusiastic about supporting me. I don't want to be a cheerleader, but I like someone to cheer me on! • Mature - My life has a good balance and flow - I want someone in my life who has this same balance and flow. Be a good role model to me. • Talk to me, not around me. Please remind others who are around me to do the same. • Respectful - I operate in my own unique way (everyone does) please respect this. • Be kind and sensitive. • Sincere • Be a safe driver • Be supportive of me & encourage me to be a good self-advocate! • Honesty - Please be honest in a kind way.

New Things I Have Learned About Myself



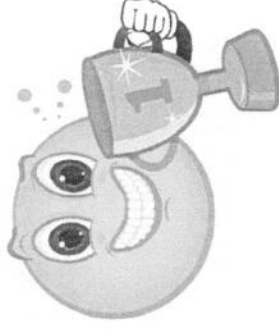
My Own Plan

What Others Need to Know or Do to Support Me

If I am going to have the things that are important to me, and stay healthy and safe, what do people need to know about me? What do they need to do? How do I need to be supported at home, at work, and when I am out in my community?

- I need others to drive me or accompany me on paratransit so that I can access my community safely.
- Stay with me - I am small and can easily get lost or overlooked.
- My parents are important, but please talk to me first. I'll let you know if we need to involve them.
- I sometimes have headaches - when I do, remind me to do deep breathing exercises. If you have suggestions for relaxation exercises, please share.
- Gently remind me to smile or maintain eye contact when trying to connect with others.
- I know how to do many things, however, sometimes I do need help to move from one thing to the next while at work and at home.
- I can be quiet and may not express myself. Please ask me questions. Give me some time to respond. (sometimes it may take longer than you think!)
- I like to write notes in my journal. If I need help taking notes, please help me.
- If I have food on my mouth, please tell me. Encourage me to check the mirror. Remind me to wipe my mouth if needed.
- Please don't tell me secrets! It makes it more stressful for me if I think that I cannot share with others.
- It feels good when I can do things for myself - if others can't hear me or see me, encourage me to speak up!
- I have to be frugal about how I spend my money. I like to do things that are fun but free or inexpensive.
- Because I am small, clothing selection can be a challenge. I need my moms help to shop for clothes.

New Things I Have Learned About Myself

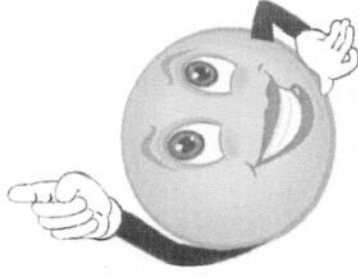


My Own Plan

What Others Need to Know or Do to Support Me (continued)

- Decision making can be difficult, please give me choices and help me way out my options. If I respond "I don't know", presenting me with choices and talking things through will help me to come up with a decision that is right for me. If I am leaning more towards yes, that usually means yes & if I am leaning more towards no, that usually means no.
- Encourage me to be a self advocate when it comes to health and safety.
- Remind me to try and do one thing at a time - (for example, I should not be eating, writing and working all at the same time)
- If I come across as demanding, gently let me know and remind me to say please, thank you and excuse me.

New Things I Have Learned About Myself



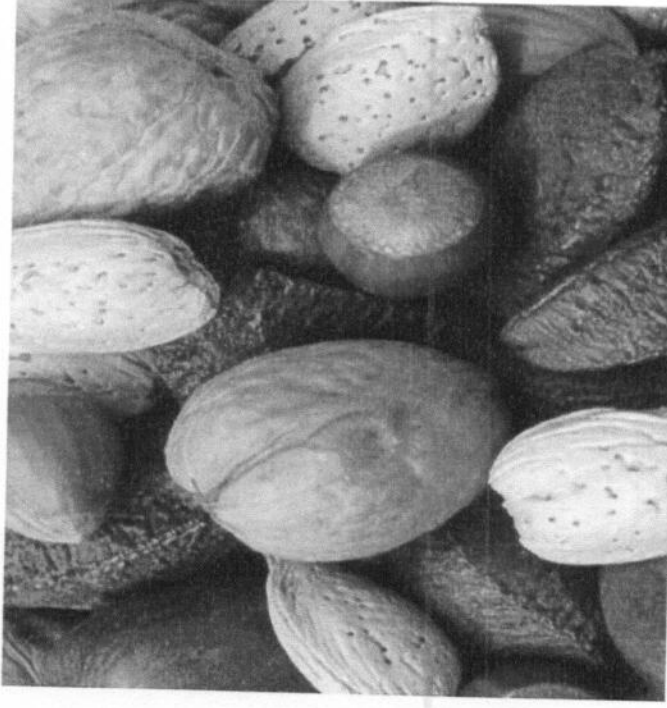
My Own Plan

What Other People Need to Know or Do to Help Me Stay Healthy and Safe

Do I have medical conditions or mental health issues that other people should know about? Are there times when I need help in managing my medical or mental health?

- My mom is my main care partner - she helps me manage any medical issues. My mom has a big red loose leaf binder with all important health history.
- I am on a soy free diet. I usually bring food with me but I can eat out! I have a list of places and foods that I can eat. Find out more about my food needs on the attached document called, "Its all about the food!"
- I need to drink. I carry Gatorade with me - sometimes I can use a gentle reminder to drink.
- I eat on a schedule of every two-three hours. I come prepared. Please provide me gentle reminders to stick to this as best as possible. Nuts provide me with protein. I have them with me. Remind me to eat them. Saying, "nuts mandy?" will also make me laugh!
- I can do relaxation exercises. Practice these with me. Share new ideas about relaxation exercises with me.

New Things I Have Learned About Myself



My Own Plan

How Do I Communicate

What is happening	What I do	What I think it means	What others should do
People talking around me	Appear to zone out or stare blankly	I'm listening but I have difficulty displaying non verbal facial cues.	Involve me in the conversation. Ask me a specific question so that I can be involved.
Appearing to be drowsy or not interested	Am less talkative and have less energy	I may not have eaten on schedule or I may be perseverating on a thought.	Remind me gently to eat. If I am perseverating, gently remind me to switch thoughts. Tell me what you observe.

What is Happening in Mandy's Life - The Upside and Downside

	What others think - their perspective	What doesn't work, doesn't make sense, the downside
<p>Look at what is working and not working, makes sense and doesn't make sense In Mandy's life <i>right</i> now. Think about ...</p> <ul style="list-style-type: none"> • Where I live • What I do during the day • Who I spend time with • The services that I receive to help you stay healthy/safe • Issues with medication - how it works, side effects • What I do for fun • Other parts of my life 	<p>What works, makes sense, the upside</p> <ul style="list-style-type: none"> • Schedule at NC job - not too little, not too many hours. • Long lunch break gives her time to eat. • Doing presentations with speakers bureau. • Consistent coaches from BOCES. Back up provided most of the time • Monica is a great. Job club counselors are great. • Control over her schedule and weekly activities. Variety in activities • Giving Mandy some down time and rest. • Enrolling in the ETP program. Paid internship once site is found. • Ability and desire to do office tasks that many others dislike or don't have time to do. 	<ul style="list-style-type: none"> • Not enough work at NC job - a lot of down time • Not enough variety in tasks. • Presentation schedule - not consistent - not reliable. • Coaches not enthusiastic. • BOCES is inflexible, unwilling to develop additional employment. • Limitation with CSS funds for agency provided coaching. • Lack of results from job developer to develop job in Queens. • Feeling that the schedule is many little things that are disjointed and not substantial enough. • Limitations on skills in office environment.

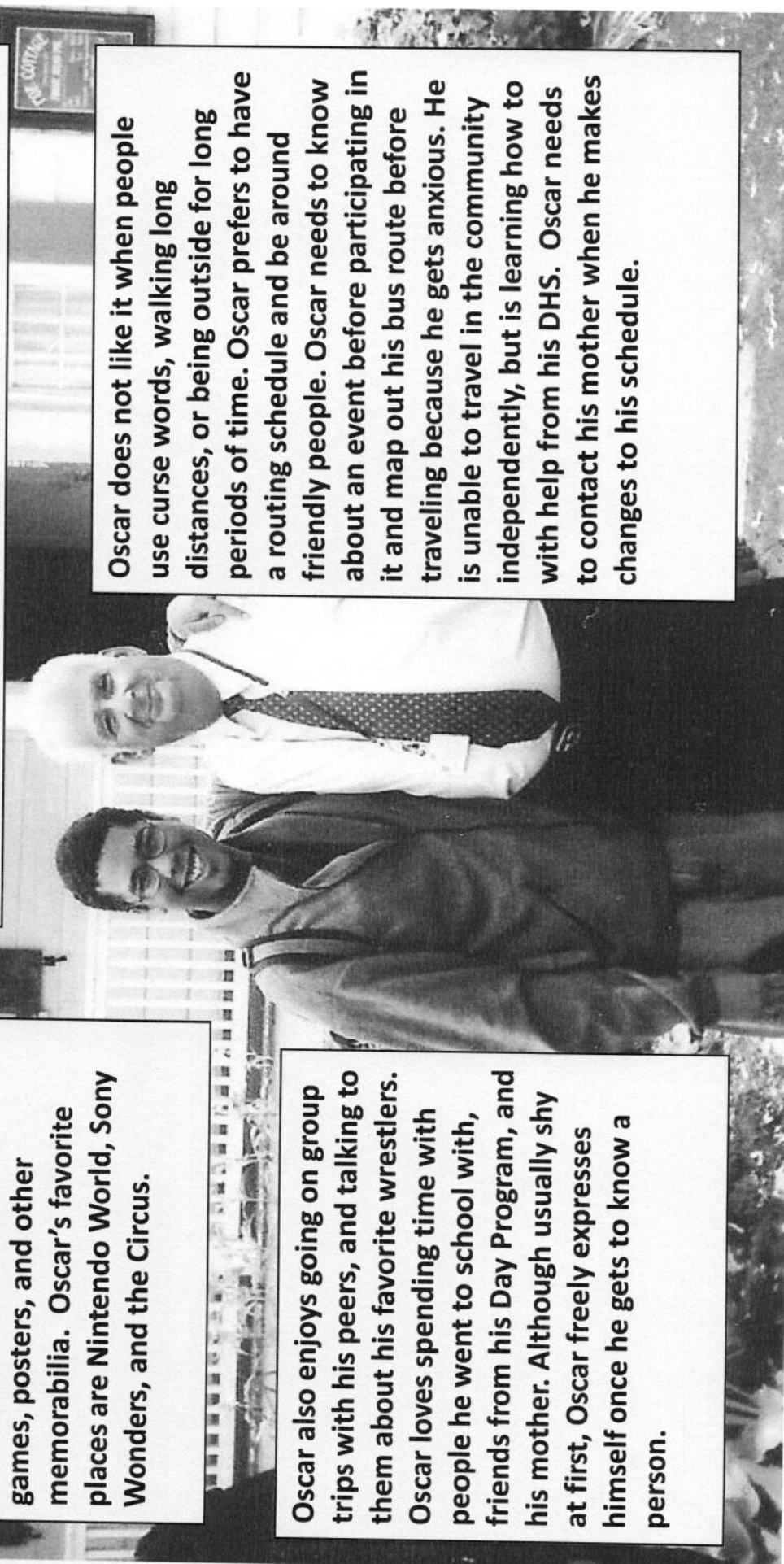
A person centered description about Oscar

Oscar enjoys being around other people and helping them if possible. He enjoys watching Wrestling and his favorite wrestler is Stone Cold Steve Austin. Oscar also collects Wrestling DVD, games, posters, and other memorabilia. Oscar's favorite places are Nintendo World, Sony Wonders, and the Circus.

To best support Oscar a person needs to know that Oscar is quiet when upset and has a hard time verbalizing his feelings. Oscar's mother is his biggest support and it is important for him to call her when he gets home from program each day.

Oscar does not like it when people use curse words, walking long distances, or being outside for long periods of time. Oscar prefers to have a routing schedule and be around friendly people. Oscar needs to know about an event before participating in it and map out his bus route before traveling because he gets anxious. He is unable to travel in the community independently, but is learning how to with help from his DHS. Oscar needs to contact his mother when he makes changes to his schedule.

Oscar also enjoys going on group trips with his peers, and talking to them about his favorite wrestlers. Oscar loves spending time with people he went to school with, friends from his Day Program, and his mother. Although usually shy at first, Oscar freely expresses himself once he gets to know a person.



Great Things about your family member

What are some great things about your family member? What do people like or admire about him or her? What are some things he or she is good at? proud of? What are some nice things that people say about them? These are important things to think about when you are figuring out the kinds of supports and services they might need. Ask these questions of people that have demonstrated they really care about your family member.

Important to your family member

What do you want other people to know about the things that are important to your family member? Who are the people that are most important to your family member? What do you do with them? What are the things that they have to do (and things they need to have) if they are going to be happy?

Characteristics of People

Who Best Support You

If you were going to pick a new person to work with your family member (e.g. case manager, staff in a home) what would you look for? What do the people that your family member like to work with have in common? Have there been people that your loved one couldn't work with? What do they have in common?

Two Minute Drill

Imagine that you are supporting your family member and you have an emergency that means you suddenly have to leave. The person who will “fill in” has arrived and you have two minutes to give advice, suggestions, or tips about supporting him or her. What would you say?

A PERSON CENTERED DESCRIPTION ABOUT _____

I. What are great things about the person?

- (What do people like and admire about the person? How does the person like to be introduced? What does the person like to do? Where does the person like to go? Whom does the person like to spend time with?)

II. What are things about the person that is important for others to know or do in order to best support them?

- (What does the person dislike? What are things that the person has to do (or have) to keep him/her happy? How does the person need to be supported at home, at work, or out in the community?)

III. What do you and other do that makes the person happy?

- (What qualities and traits do you possess that the person likes? What qualities and traits do other people possess that the person likes?)

IV. Is there anything else that you can share that we would want to know about the person?

Written by: _____ Relationship to person: _____

Guardianship and Alternatives

- Individuals with intellectual disabilities do not automatically require guardianship
- All people receive assistance from family, friends or professionals when making major life decisions.

Guardianship and Alternatives

- Power of attorney for legal or medical issues
- Health Care Proxy
- Circles of Support
- HIPAA authorization
- Representative Payee
- Trustee (special needs trusts)
- Limited Guardianship
- Estate Planning & Wills
- Surrogate Decision Making