

# "Guide to Becoming Independent!"

New Hampshire Family Voices Youth for Education, Advocacy and Healthcare (YEAH) Council



### "YEAH"

#### Youth for Education, Advocacy and Healthcare Council

Thank-you for obtaining a copy of "Ready? Get Set. Go!... The YEAH Council thought that it was a useful tool and wanted to share it with other youth with chronic health conditions.

The YEAH (Youth for Education, Advocacy and Healthcare) Council is made up of youth and young adults with varying special health care needs and is facilitated by Karin Harvey-Olson. The group comes together monthly to discuss issues involved in what it means to be a young adult with a chronic health condition, and how best to make the transition to the adult healthcare system. The Council works to educate other youth on how to handle their transition to adulthood, as well as educating the medical professionals about what they can do to facilitate the transition from pediatric medical care to adult medical care.

We are here to help teens and young adults:

- get the information they need to live independently

- live a successful life

- make decisions about healthcare

- inform your doctors and specialists about your healthcare and general needs
  - make information easily available to teens who may lack parental guidance

For more information contact YEAH E-Mail: yeahcouncil@nhfv.org Web: http://yeah-councilnh.com

This publication is available on line at www.nhfv.org

## Instructions for My Life My Health Checklist... Ready? Get Set. Go!

#### 1. My Life, My Health Checklists What are they?

It is a series of checklists: Ready? Get Set. Go! Designed to help young people and families develop skills for growing up and getting ready for the future.

#### 2. Why were the checklists developed?

The checklists were developed as part of a frame work for transition planning. They help youth and their families begin preparations for adulthood at an early age by setting goals and making plans for all levels of development.

#### 3. Who are the checklists for?

- The checklists are designed for all young people and their families.
- Professionals can play a key role in introducing the checklists to youth and families and supporting them in making action plans for the goals they identify.

## 4. How do young people and their families use the checklists?

- Young people and their families should answer the questions and use the checklists as tools to identify areas of learning and to provoke questions to explore as a young adult, a family, or with a healthcare provider.
- The intent is that young people and their families will keep, refer, and update them.
- When fist getting started, parents may take a leadership role in using the checklists.
   When developmentally appropriate, the young person should gradually take an increasing responsibility for goal setting and planning.



★ Items in the checklists are designed to encourage conversation about growing up, making choices and participating actively in life.

Some items may not seem relevant to all young people and their families. They may leave the item off their list. Or, parents may adjust the wording to suit their unique goal. Or, the item may simply serve as a reminder for parents to plan ahead for that aspect of growing up.

#### A Shared Management Model

This is an approach for transition planning and is the framework from which the checklists were based.

A therapeutic alliance between youth, families, schools, and service providers is essential to allow young people with special health care needs to develop into independent, healthy, functioning adults.

Roles of players in the alliance change as the young person grows up. Leadership is gradually shifted in the planned, systematic, and developmentally appropriate way from the parent and service providers to the young person.

#### 5. Service Providers Can:

- Encourage youth and families to use the checklists to set goals and make plans for developing skills for growing up.
- Assist families in making action plans to meet their identified goals; suggest workshops, services, resources, or strategies that may encourage and help them.
- Raise developmentally appropriate life skills in goal discussions if young people and their families do not.
- Incorporate life skills goals in service plans, 504 Plans, and Individualized Education Plans (IEP).
- Ask what goals they are currently working on.
- Reflect on how you can incorporate the shared management model into your work.
- 6. Which Checklists should the young person & family use?
  - The checklists include a developmental progression of skills.
  - The young person and family move from one checklist to another based on their level of preparation for adulthood. For example, an 11 year-old may be using *Ready?* And another may be using *Get Set*.
  - More than one may be used at a time.

## 7. Are there specific age ranges for these checklists?

Generally speaking, the checklists may be appropriate for the following age ranges.

> Ready? Ages 7-12 Get Set ages 13-16 Go! Ages 17 and older

Every young person will move through the checklists at his or her own pace. When you review goals and progress with the young person and their families, discuss with them if they feel they are ready for the next checklist in the series.



Ready? is for youth and families just starting to think about growing up and is to be used as early as possible.

As early as age 7, young people can think about the statement, "I ask at least one question during a health care visit".



Get Set is for those who have taken some steps in planning for the future and focus on next steps.

Young people can work on "I ask my doctor questions during healthcare visits".



Go! Is for those nearly ready to transition into adult services. Young people address "I ask most questions during a healthcare visit".

- 8. Tips for service providers helping a young person transitioning to adulthood:
  - Speak directly to the young person whenever possible. When appropriate, suggest meeting alone with the young person for a portion of the time.
  - Direct questions to the young person. Ask the young person if they have any questions.
  - Provide choice and discuss options with the young person, requesting their input.

# Tips for building self-determination

#### **Making Choices**

• If you have a disability, learn about it

 Find your strengths, interests, and think creatively about learning styles and methods

 Have high expectations for yourself

• Explore new activities; find positive, fun things to do with your friends. Learn from your mistakes

 Have a say in things that are about you

 Be open minded and listen to what people you trust have to say

#### Self Advocacy

Speak up

 Take on a leadership role in something you are good at

• Don't be afraid to ask for help

 Learn to talk about your
 Disability. Help others to understand you and your needs

 Work on creating open, nonjudgmental relationships

#### Exploring the Possibilities

 Try to learn something new every day

 Volunteer in something that interests you; find new hobbies

- Find adult mentors who understand and relate to you
- Talk about your future

#### Strong Self-Esteem

- Write your thoughts down; describe yourself and your life
- Take steps to feel part of your community; get involved by volunteering
- Use your talents
- Involve yourself in healthy, caring relationships

 Surround yourself with people who are positive; find someone you look up to to be your mentor

#### Goals & Plans

 Understand what a goal is and why they are important

 Think about what you want to do with your life, discuss this and other interests you have with people who are important to you

 Make a list of your goals and the steps you need to take in order to reach them

• Be flexible and realistic about your goals

Surround yourself with people who are positive; find someone you look up to to be your mentor

#### Understand Reasonable Risks

 Think about all of the benefits and consequences before you take action

- Know your support network;
   those people who will be there for you unconditionally
- Seek advice from others but keep in mind that sometimes the truth is not easy to hear
- Mistakes are normal and an important part of learning

#### **Problem Solve**

- Learn to take ownership of challenges
- Accept the idea that problems are part of healthy development
- Create a list of positives and negatives to help you make good decisions
- Get advice from people you trust



### Notes to myself

Who do I need to talk to about my disability? Write down the names of people you think you should talk to (parents, healthcare professionals, friends, mentors, etc.).

Where do I need to go to get information? Write down the places you need to visit or resources that you can use (local community center, Internet websites, library, doctor's office etc.).



Ready?

# my life my health

**R E A D Y**? is for young people who have begun to think about the future and the challenges that come with growing up. Items in this checklist will help you begin to develop the skills you need for growing up. It may be a good idea to work together with your family to complete this checklist. This may give you a chance to talk about how you can work together as a team to get ready for your future.

Along with the checklist you will find a description of the stages of healthy development; this chart outlines some typical feelings and behaviors youth experience during adolescence. These stages can be a challenge for adolescents, especially for those who develop early, later, or have special healthcare needs.

EACH STAGE OF LIFE BRINGS CHANGES THAT WE NEED TO ADJUST TO IN ORDER TO LIVE A HEALTHY, PRODUCTIVE, AND HAPPY LIFE. YOU HAVE ALREADY GONE THROUGH MANY CHANGES AS YOU HAVE GROWN FROM INFANCY, TO CHILDHOOD, TO EARLY ADOLESCENCE, WHERE YOU ARE TODAY.

MY LIFE, MY HEALTH IS A SERIES OF THREE CHECKLISTS: READY? GET SET, GO!. THESE CHECKLISTS WILL HELP YOU PREPARE FOR THE FUTURE, THINK ABOUT WHAT YOU NEED TO WORK ON, AND PLAN HOW YOU WILL DO IT. READY? IS THE FIRST LEVEL OF THE SERIES.

## My life, my health.... Ready?

There are items in this checklist that may or may not apply to you. Challenge yourself to think creatively about each item.

	Something I want to work on	WHAT I NEED TO DO?	Done
Self-Advocacy			
I think and talk about my future.	YN		
I can talk about what I need and want.	YN		
Social & Recreation			
I spend time with my friends.	YN		
I go to programs in my community.	YN		
I know how to use the Internet safely.	YN		
Independent Living Skills			
I know my home phone number and address.	YN		
I know how to use the phone in an emergency.	YN		
I know how to get help in an emergency.	YN		
I can make my own meals or if unable, I can tell someone how to make it for me.	YN		
I am responsible for my chores.	YN		
I pick out my own clothes.	YN		
I take care of my own belongings.	YN		
I know my personal care routine (daily hygiene, grooming, etc.).	YN		
I have an allowance and I know how to spend it responsibly.	YN		
I know what healthcare supplies I need (medications, sanitary, catheter, etc.).	YN		
I know about assistive devices and technology.	YN		

	Something I want to work on	WHAT I NEED TO DO?	Done	
School & Work				
I am responsible for getting my homework done.	YN			
I talk about what I want my career to be.	YN			
I go to IEP/504 meetings at school.	YN			
Health & Wellness				
I know my height and weight.	YN			
I exercise daily and try to eat healthy.	YN			
I know how puberty will affect me.	YN			
I know when I am sick.	YN			
I can explain my disability and how it affects me.	YN			
I meet alone with my doctor for part of the time during my visit.	YN			
I ask my doctor at least one ques- tion during my visits.	YN			
I answer at least one question dur- ing my visits.	YN			
I have talked with my doctor about my health and setting goals.	YN			
I have talked with my doctor about going to different doctors when I am an adult.	YN			

The decision to move on to the next checklist is up to you. You can use the DONE column to help you decide. If you have a checkmark ✓ beside each item that you wanted to work on, move on to the next checklist: GET SET.

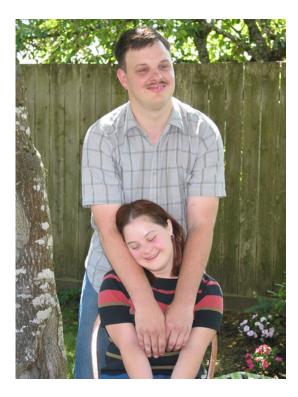
NOW THAT YOU HAVE COMPLETEDTHE FIRST CHECKLIST, TAKE SOME TIME TO THINK ABOUT WHAT YOU HAVE LEARNED ABOUT YOURSELF.

Did READY? help you to ...

think more about your future? find ways to be more responsible and develop decision making skills? think about the things you need to work on? feel okay about the changes happening to your body?

#### Adolescent Development Chart

PHYSICAL GROWTH		
EARLY	EARLY	LATE
• Your body and feelings grow and	<ul> <li>Your body starts to look more</li> </ul>	<ul> <li>Growth begins to slow as you reach</li> </ul>
change.	like an adult's body than a kid's	physical and reproductive maturity.
	body.	
KNOWLEDGE AND UNDERSTANDING	G	
EARLY	MIDDLE	LATE
<ul> <li>You think mostly about the "here and now" and how you feel.</li> </ul>	• You notice things are more complicated then they used to be. Sometimes you need to work	<ul> <li>You are learning to think about things on many levels to see the big picture.</li> </ul>
	harder for the things you want and need.	<ul> <li>You are able to understand, plan, and pursue long-range goals.</li> </ul>
DEPENDENT/ INDEPENDENT		
EARLY	MIDDLE	LATE
• Your parents tell you to do more around the house. One minute they say "you're too old for that," the next they say "you're not old enough." You feel you've outgrown your toys/clothes/games.	• You get into more conflicts with your parents and family mem- bers. You are more private and don't want to tell them every- thing. You feel your parents are over protective and don't under- stand you.	• You are free to make your own choices and decisions and that involves taking responsibility for any consequences.
<ul> <li>Your mood changes quickly, you go from happy to bored to sad.</li> </ul>		
BODY IMAGE		
EARLY	MIDDLE	LATE
• You compare your body to your friends'. You worry about how you look, and what people think of you.	• You are okay with the physical changes but worry more about your personal "attractiveness." Sometimes you are full of energy and other times you just want to lay around.	• You are much more comfortable with yourself and how you look.
PEER GROUP		
EARLY	MIDDLE	LATE
• Very close friendships tend to be with people of the same sex as you. Contact with the opposite sex usually happens in groups.	• You tend to associate with a certain group, team, click, gang etc. You begin to explore your ability to attract a partner and date.	• Your friends do not influence your ideas and decisions as much. Your choice in a partner or friend is based on your individual ideas and values and not your friends preferences.
IDENTITY		
EARLY	MIDDLE	LATE
<ul> <li>You question "Am I normal?"</li> <li>You daydream a lot and think</li> <li>"no one understands me."</li> <li>You like to be alone.</li> </ul>	• You may start to explore new things – like new friends, jobs, intimate relationships, or try things that you aren't sure are safe or right.	<ul> <li>You start to see your family in a new way, you relate to them as an adult.</li> <li>You have your own ethical and moral values.</li> <li>You have realistic career goals and you know your limitations.</li> <li>You are more capable of intimate and complex relationships.</li> </ul>





# my life my health

 $G \in T$   $S \in T$  is for young people who have established some independence and are thinking about planning for their future. Items in this checklist can be used as a guide to thinking creatively about responsibility, growing up, and setting goals. It may be a good idea to work together with your family to complete this checklist. This may give you a chance to talk about how you can work together as a team to get ready for your future.

EACH STAGE OF LIFE BRINGS CHANGES THAT WE NEED TO ADJUST TO IN ORDER TO LIVE A HEALTHY, PRODUCTIVE, AND HAPPY LIFE. YOU HAVE ALREADY GONE THROUGH MANY CHANGES AS YOU HAVE GROWN FROM INFANCY, TO CHILDHOOD, TO EARLY ADOLESCENCE, WHERE YOU ARE TODAY. Along with the checklist you will find a description of the stages of healthy development; this chart outlines some typical feelings and behaviors youth experience during adolescence. These stages can be a challenge for adolescents, especially for those who develop early, later, or have special healthcare needs. On the backside of the chart you will find some helpful tips on building self-determination, these tips may give you ideas on how to build the skills you need to transition from a child to an adult.

MY LIFE, MY HEALTH IS A SERIES OF THREE CHECKLISTS: READY? GET SET, GO!. THESE CHECKLISTS WILL HELP YOU PREPARE FOR THE FUTURE, THINK ABOUT WHAT YOU NEED TO WORK ON, AND PLAN HOW YOU WILL DO IT. GET SET IS THE MIDDLE LEVEL OF THE SERIES.

## My life, my health.... Get set.

There are items in this checklist that may or may not apply to you. Challenge yourself to think creatively about each item.

	Something I Want to Work on	WHAT I NEED TO DO?	Done ✓
Self-Advocacy	WORK ON		
I know about my right to privacy, making decisions, and giving permis- sion on certain things in my life.	YN		
I know my legal rights as a person with a disability.	YN		
Social & Recreation			
I spend time with my friends outside of school.	Y N		
I know about dating and safe sex.	YN		
I pick my own programs and activities.	Y N		
Independent Living Skills			
I make meals with my family.	Y N		
I help with grocery shopping.	Y N		
I am responsible for a few chores.	Y N		
I pick out my clothes.	Y N		
I take care of my belongings.	Y N		
I manage my personal care routine.	Y N		
I can access my bank account.	Y N		
I can buy things I need (clothes, CD's, school supplies) and know where to get them.	YN		
I am learning to safely get around my community.	Y N		
I am learning to use public transportation.	Y N		
I can be home alone.	Y N		
I know how to get the healthcare supplies I need.	Y N		
I take responsibility for my equip- ment (wheelchair repair, ordering new supplies).	Y N		
I have tried assistive devices and technology.	Y N		
I know what to do in an emergency.	YN		
I talk about where I would like to live in the future.	Y N		

	Something I Want to Work on	WHAT I NEED TO DO?	Done ✓
School & Work			
I do homework by myself.	Y N		
I know how my disability affects my			
learning.	Y N		
I know the supports and strategies I need			
to be successful in school.	YN		
I take part in planning for my education			
(guidance, IEP or 504 meetings).	Y N		
I know what my skills and interests are			
related to my career choices.	YN		
I talk about my plans after high school.	Y N		
I explore volunteer and/or part-time job			
opportunities.	YN		
Health & Wellness			
I try to exercise daily and eat healthy.	Y N		
I am happy with my body.	Y N		
I know the risks of smoking and using			
alcohol and drugs.	Y N		
I know who to talk to in difficult times.	Y N		
I recognize the changes I am			
experiencing during puberty.	Y N		
I know what medications I take and I			
know how much and when to take them.	Y N		
I meet alone with my doctor.	Y N		
I have talked with my doctor about health			
& wellness goals.	Y N		
I ask my doctor questions during my visit.	Y N		
I answer questions during my visit.	Y N		
I take part in making medical decisions.	Y N		
I keep a record of my healthcare			
information.	Y N		
I talk with my doctor about adult			
services.	Y N		
<i>I</i> have talked with my doctor about the			
things I should think about when choosing	YN		
an adult doctor/specialist.	T IN		
I have talked with older siblings or			
friends about healthcare transition.	Y N		
Healthcare System			
I know the date and reason for my next	Y N		
doctor's appointment.			
I can call my doctor's office to make or	Y N		
change an appointment.			
I know the name of my health insurance	Y N		
and information about how it works.			
I know the difference between primary	Y N		
and specialty care providers.			

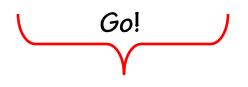
The decision to move on to the next checklist is up to you. You can use the DONE column to help you decide. If you have a checkmark ✓ beside each item that you wanted to work on, move on to the next checklist: GET SET.

NOW THAT YOU HAVE COMPLETEDTHE FIRST CHECKLIST, TAKE SOME TIME TO THINK ABOUT WHAT YOU HAVE LEARNED ABOUT YOURSELF.

Did GET SET help you to ...

think more about your future? find ways to be more responsible and develop decision making skills? think about the things you need to work on? feel okay about the changes happening to your body?





# my life my health

**GO** is for young people who have established some independence and are thinking about planning for their future. Items in this checklist can be used as a guide to thinking creatively about responsibility, growing up, and setting goals. It may be a good idea to work together with your family to complete this checklist. This may give you a chance to talk about how you can work together as a team to get ready for your future.

Along with the checklist you will find a description of the stages of healthy development; this chart outlines some typical feelings and behaviors youth experience during adolescence. These stages can be a challenge for adolescents, especially for those who develop early, later, or have special healthcare needs. On the backside of the chart you will find some helpful tips on building self-determination, these tips may give you ideas on how to build the skills you need to transition from a child to an adult.

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## My life, my health.... Go!

There are items in this checklist that may or may not apply to you. Challenge yourself to think creatively about each item.

	Something I Want to Work on	WHAT I NEED TO DO?	Done
Self-Advocacy	I		
I know about my role in the family and how it will change when I become an adult.	YN		
I know where to find support and information.	YN		
Social & Recreation			
I make plans to spend time with my friends	YN		
I participate in youth or adult social and recreation activities.	YN		
I know about safe sex and healthy relationships.	YN		
I have adults in my life who care about me other than my parents (e.g. teacher, mentor, coach, uncle, religious leader).	YN		
Independent Living Skills			
Independent Living Skills I prepare meals or if unable, can tell someone how to do it.	Y N		
I prepare meals or if unable, can tell	Y N		
I prepare meals or if unable, can tell someone how to do it. I can do my own laundry or if unable,			
I prepare meals or if unable, can tell someone how to do it. I can do my own laundry or if unable, can tell someone how to do it. I take care of my personal care needs or if unable, can tell someone	Y N		
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I prepare meals or if unable, can tell someone how to do it. I can do my own laundry or if unable, can tell someone how to do it. I take care of my personal care needs or if unable, can tell someone how to do it. I manage my budget.	Y N		
I prepare meals or if unable, can tell someone how to do it. I can do my own laundry or if unable, can tell someone how to do it. I take care of my personal care needs or if unable, can tell someone how to do it. I manage my budget. I go out in my community on my own. I take public transportation on my	Y N Y N		
I prepare meals or if unable, can tell someone how to do it. I can do my own laundry or if unable, can tell someone how to do it. I take care of my personal care needs or if unable, can tell someone how to do it. I manage my budget. I go out in my community on my own. I take public transportation on my own.	Y N Y N Y N Y N		
I prepare meals or if unable, can tell someone how to do it. I can do my own laundry or if unable, can tell someone how to do it. I take care of my personal care needs or if unable, can tell someone how to do it. I manage my budget. I go out in my community on my own. I take public transportation on my own. I can drive. I have assistive devices and the	Y N Y N Y N Y N Y N		

	Something I want to work on	WHAT I NEED TO DO?	DONE
School & Work			
I have a plan for after high school.	Y N		
I have a volunteer position and/or summer or			
part-time job.	Y N		
I have a career goal.	Y N		
I know what I need to do to be successful in			
college/education program, or a job.	Y N		
I know how to make my disability known	Y N		
in a job interview or college/education program.			
Health & Wellness			
I know about sexual health, family	YN		
planning, and genetics.	T IN		
I have personal health & wellness goals and un-			
derstand the risks of an unhealthy lifestyle.	Y N		
I know what medications to take for things like a			
cold, headache, and stomachache.	Y N		
I refill my medications when it is time.	Y N		
I can explain my medical history.	Y N		
I can contact my doctors to schedule appoint-			
ments and can tell them about any changes in my	Y N		
health.			
I go to my appointments alone or choose someone	Y N		
to assist me.	Y N		
I decide what treatments I need with my doctor			
and I sign my medical consent forms.	Y N		
My doctor and I have talked about adult doctors	YN		
and specialists.			
I am writing a Portable Medical Summary			
of my medical diagnosis, history, allergies,	Y N		
treatments, and emergency information.			
Healthcare System			
I can tell someone about how my health			
insurance works like how much my co-pay is and	Y N		
about the services available to me.			
I know if I receive SSI (Supplemental Security			
Income) and if I will be eligible for SSI when I	Y N		
am 18.			
I know how long I will be covered under my			
parent's health insurance plan and what I need to	Y N		
do to keep my coverage.			
I know what my legal rights and responsibilities			
will be when I turn 18 years old (sign medical	Y N		
consent forms, make medical decisions by			
myself).			
I am planning for my transfer to adult	Y N		
healthcare.			

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New Hampshire FAMILY VOICES®