Creating Positive Outcomes in the Glut 1 Life

2017 Glut 1 Deficiency Foundation Conference
July 13-14
Nashville, TN
Meet~ share and learn!
Who am I?
Our family...........
How it started...............
Creating Positive Outcomes in Glut 1 Life Outline

- Resources
- Planning for a “Good Life”
- Sharing of ideas to create independence with Glut 1
Creating Positive Outcomes Start Early

We are not given a good life or a bad life. We are given a life. It’s up to us to make it good or bad.
Resources..........(aka the need to know stuff)

- Early intervention is key ~ by law, all states must offer early intervention programs
- School services ~ every state has to start services at age 3 until 22\textsuperscript{nd} bday.
  - Interventions might be~ Music, HIPPO, OT, PT, Speech, learning accommodations
  - Individualized based on need
- State programs-Waivers-waive parental income

- For additional information-
  - Thearc.org
  - Familyvoices.org
  - ADA.gov
Resources........ (again need to know....)

Supported Decision Making
~Going to family, friends, or experts for advice or guidance on making a decision.

- Helps teach individuals the skills needed to make decisions
- Helps teach the things to consider when making decisions
- Helps teach how to evaluate opinions
Power of Attorney

- Very common among seniors and the military
- Threshold does the person understand they are giving you the right to act on their behalf?
- Gives POA access to information and the ability to make decisions for the individual
POWER OF ATTORNEY - PRO’s

- No Court! Just needs to be notarized
- Can have an attorney draft a specific document or download from legal websites
- Allows independence
- Allows the individual to keep their rights
Power of Attorney - Considerations....

- Revocable
- Easily transferable
- If the POA and the individual disagree, the individual choice trumps the POA
Guardianship and Alternatives

3 types of Guardianship

- Guardian of the Person living conditions, treatment
- Guardian of the Estate finances, legal issues
- Plenary Guardianship—”Full Guardianship”—
  - Guardianship of the Person and the Estate
More extreme than people realize—really hard as a parent

- No authority to make decisions
- Must have an attorney and go to court
- Really about the person with a disability
- Going to court and having the person declared a “protected person” by the court
  - Must prove the person is incompetent to make decisions
  - Stripping the individual of the right to do things and make decisions
- Costs $750-$2,000
How to end guardianship.....

- Must be overturned by the Court
- Does not end when the guardian wants to stop
- Need to have successor guardian or co-guardian in place
- Some volunteer guardianship programs, professional guardians
- To overturn guardianship, the Protected Person must prove they no longer need a guardian
Two Different Social Security Disability Programs

Supplemental Security Income (SSI)
- Designed for people who are Aged, Blind, or Disabled and have very low income and very few resources
- Maximum benefit in 2016 is $733 per month

Social Security Disability Insurance (SSDI)
- Designed for people who have earned at least 20 work credits and become disabled
- Benefit amount based on work history
- Disabled Adult Children-disabled individual based on parents work performance.

Social Security Administration decides which is appropriate
Apply for SSI benefits-

- Typically, you want to apply when the individual turns 18
- If an individual received Social Security benefits as a child, must reapply as an adult
- Different eligibility requirements for adults and children
Creating Positive Outcomes Start Early

How we spend our days is, how we spend our lives.
LifeCourse Framework

- Created by families
  - to help individuals and families of all abilities and all ages develop a vision for a good life;
  - think about what they need to know and do;
  - identify how to find or develop supports;
  - discover what it takes to live the lives they want to live.

- Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to think about life experiences that will help move them toward an inclusive, productive life in the future.
Core Belief

All people have the right to live, love, work, play and pursue their life aspirations in their community.
Communities of Practice

- Alabama
- Delaware
- Hawaii
- Indiana ***
- Kansas
- Kentucky
- Maryland
- Ohio
- Oregon
- Pennsylvania
- South Dakota
People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life, including daily living, safety & security, community living, healthy lifestyle, social and spirituality, and citizenship and advocacy.
Life Stages

The *LifeCourse Framework* looks at areas across the life span. Our lives are not disconnected stages, each stage influences all the rest that follow. This perspective takes into account the complex interplay of biological, behavioral, psychological, social, and environmental factors.

- **Prenatal/infancy**: Early years, wondering if meeting developmental milestones
- **Early childhood**: Preschool age, getting a diagnosis
- **School age**: Everyday life during the school years
- **Transition**: Transitioning from school to adult life
- **Adulthood**: Living life as an adult
- **Aging**: Aging and preparing for end of life (parent/family/individual)
Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don’t want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.
# Tool for Developing a Vision - Family

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help families of all ages – those with a very young child, an adult or somewhere in between, start to think about a vision for how their family member will live their life as an adult.

<table>
<thead>
<tr>
<th>Life Domain</th>
<th>My Vision for My Family Member's Future</th>
<th>Priority</th>
<th>Current Situation/Things to Work On</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Life Employment</td>
<td>What do I think my family member will be doing the day in his/her adult life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Living</td>
<td>Where and with whom do I think my family member will live in his/her adult life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social &amp; Spirituality</td>
<td>How will he/she connect with spiritual and leisure activities, have friendships and relationships in his/her adult life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy Living</td>
<td>How will he/she live a healthy lifestyle and manage health care supports in his/her adult life?</td>
<td></td>
<td></td>
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<td>Safety &amp; Security</td>
<td>How will I ensure safety from financial, emotional, physical or sexual harm in adult life?</td>
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<tr>
<td>Citizenship &amp; Advocacy</td>
<td>How can I make sure he/she has valued roles and responsibilities, and has control of how he/she runs his/her own life is lived as an adult?</td>
<td></td>
<td></td>
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<tr>
<td>Supports for Family</td>
<td>What will our family need to help support him/her to live a quality life as an adult?</td>
<td></td>
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<tr>
<td>Supports &amp; Services</td>
<td>How will he/she be supported in adult life to lead the kind of life he/she wants as independently as possible?</td>
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Individuals and Families utilize an array of integrated supports to achieve the envision good life including:

- Technology
- Personal Strengths & Assets
- Relationships
- Community Based
- Eligibility Specific
Integrated Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

Access the LifeCourse framework and tools at lifecoursetools.com

Developed by the UMKC Institute for Human Development, UGEDO. More tools and materials at lifecoursetools.com

MAY 2016
Life Outcomes

Individuals and families focus on life experiences that point the trajectory toward a good quality of life. Based on current support structures that focus on self-determination, community living, social capital and economic sufficiency, the emphasis is on planning for life outcomes, not just services.
What is Good Life.....

- We need to discover what the Good Life looks like for each person.
- Are you living or existing?
- What brings you joy?
- How are your days spent?
- How is your life’s vision reflected in your day?
Additional Resources

http://mofamilytofamily.org/projects/lifecourse-tools/

http://supportstofamilies.org/

http://www.lifecoursetools.com/
Tools to create independence~

HAPPINESS IS

...being independent.

Disclaimer-I am not a dietician nor a doctor. This is solely based on our programming and what we have done with Chris.
<table>
<thead>
<tr>
<th>Energy Level</th>
<th>Description</th>
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<tbody>
<tr>
<td>5</td>
<td>I feel GREAT!</td>
</tr>
<tr>
<td>4</td>
<td>I feel good.</td>
</tr>
<tr>
<td>3</td>
<td>I feel OK.</td>
</tr>
<tr>
<td>2</td>
<td>I am having trouble focusing</td>
</tr>
<tr>
<td>1</td>
<td>I feel bad. I need a break!</td>
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Tracking Energy
How do I feel? Understanding energy?

- Use and review the scale repeatedly.
- Had Chris evaluate himself and then other person evaluate as well.
  - Chris starting to get the look-right away
    - Compare numbers with the evaluator
    - Eventually do it on his own
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<th>Time</th>
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<th>Did you eat bomb?</th>
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<tr>
<td>9:00 AM</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>10:00 AM</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>11:00 AM</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>12:00 PM</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>1:00 PM</td>
<td>5</td>
<td>yes</td>
</tr>
<tr>
<td>2:00 PM</td>
<td>5</td>
<td></td>
</tr>
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All numbers in blue are Mrs. Baker’s ratings. Chris said he can’t rate himself at work because he’s doing trays.

**Seizures- 3 at school**

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Independence with diet!
Snack

½ cup of Strawberries

3 (2 TBSP) of Cream + Water + Flavoring
Guys- I can do it myself!!!
### Dinner Meal Card

#### Pick a MEAT
- **Meat Options:** Chicken, Steak, Wrist, Fish
- **Measurement:** About the size of my hand:
  - Chicken: 8
  - Steak: 8
  - Wrist: 8
  - Fish: 8

#### Pick a VEGGIE
- **Vegetable Options:** Broccoli, Cauliflower, Turnips, Green Beans
- **Measurement:**
  - Broccoli: 1/2 Cup
  - Cauliflower: 1/2 Cup
  - Turnips: 1/2 Cup
  - Green Beans: 1/4 Cup

#### Pick a FRUIT
- **Fruit Options:** Strawberries, Blueberries, Blackberries, Raspberries
- **Measurement:**
  - Strawberries: 1/2 Cup
  - Blueberries: 1/2 Cup
  - Blackberries: 1/4 Cup
  - Raspberries: 1/4 Cup

*Don't forget your oil!!!*
Grande
Iced Passion Tea
No Classic
Heavy Cream
With Sugar Free Vanilla