Today’s Agenda

• Planning for the future
• Building a base
• Building skills for competency and success
• Building opportunities for happiness and well-being
Sometimes you need a map to know where you’re going...
How to get parents to start thinking long-term?

- Housing
- Employment
- Higher-education
- Support system
- Financial Security
- Self-help skills
Questions to ask Parents

What kind of life do you want for your son or daughter?

What kind of life would your son or daughter want?

What expectations do you have for your other children?

Do you want your son or daughter to have choices?

Do you want your son or daughter to be able to express their wishes?
What parents often plan for

- Funding
- Special Needs Trust
- Guardianship
- Housing
- Medical Care
But what’s most important to the Individual?
Self Determination

People with disabilities have the right and ability to **choose** and **control** their own quality of life, goals, and services.

http://www.fulllifehawaii.org/selfdetermination.html
Consider Self Determination when planning for the child’s future.

- Services
- Staff
- Housing
- Roommates
- Employment
- Guardian
- Classes
- Dinner
- Cereal choices
- What chore to do first
- Clothing
- Friends
- Movie
- How to spend allowance
Choice

Giving choices can

• Give a person a sense of control
• Reduce problem behavior
• Aid in the development of self-determination
Embedding Choice into Daily Routines

• Choices during free time
• Choosing which chore to complete first
• Choosing breakfast cereals at the grocery
• Choosing snack items after school
• Choosing what to wear in the morning
Planning for the future: Maslow’s Hierarchy of Needs

- **Physiological needs**: Basic needs such as funding, Special Needs Trust, Guardianship, Plan B
- **Safety needs**: Psychological needs such as work at school and home to build skills for competency and success
- **Belonging and love needs**: Self-fulfillment needs: Feeling accomplished, being creative
- **Esteem needs**: Psychological Needs: Work at school and home to build skills for competency and success
- **Self-actualization**: Basic Needs: Funding, Special Needs Trust, Guardianship, Plan B
Building a Base
Special Needs Trusts

Purpose: Protect benefits of beneficiary, and increase quality of life

- Must be set up by a lawyer
- Lots of rules
- A “trustee” is responsible for the SNT
- Money in the trust not “countable income” for beneficiary

Yussman (2010).
Special Needs Trusts

First Party Trust is sometimes called “self-settled”, “Medicaid Payback Trust”, or “Pooled Trust”

Third Party SNT is usually created by relatives’ estate plans

Yussman (2010)
Who can have a SNT?

Person with a “disability”, as defined with social security determination

Yussman (2010)
Examples of what a trust may be able to pay for can be paid for by the trustee of the SNT:

Out-of-pocket medical and dental expenses; Home improvements; Medical equipment not provided by Medicaid; Computers, etc; Eyeglasses; Cable TV; Exercise equipment; Telephones, TVs, radios; Annual independent checkups; Cameras; Transportation;
SNT

• Overview of Special Needs Trust Webinar
  – Richard Bush

• https://louisville.edu/education/kyautismtraining/videos
Guardianship

“Guardianship is a legal tool that grants a parent or other adult the legal authority to make decisions for a legally disabled adult.”

http://www.kypa.net/drupal/?q=taxonomy/term/132
Guardianship

Depending upon the specific rights the court takes away, the guardian’s duties may include:

• Arranging for a place for the ward to live in the least restrictive environment

• Arranging for educational, social, vocational, and rehabilitation services

• Arranging for other services the ward needs to meet his needs

• Consenting to medical treatment for the ward

• Managing the ward's finances, unless the court has appointed a separate conservator

http://www.kypa.net/drupal/?q=taxonomy/term/132
Guardianship

A guardian MAY NOT consent to abortion, sterilization, psycho-surgery, removal of a bodily organ, or amputation of a limb without court approval unless there is an emergency that requires it.

http://www.kypa.net/drupal/?q=taxonomy/term/132
Levels of Guardianship

**Full guardian** if the person is unable to take care of all his personal needs

**Limited guardian** if a person can take care of some personal needs but needs help in other areas

**Conservator** if the person only needs help with his finances

**Both** a conservator and a guardian

http://www.kypa.net/drupal/?q=taxonomy/term/132
Alternatives to Guardianship

• Advance Directives
• Bank Account Requiring Co-Signatures
• Citizen Advocacy
• Curator
• General Adult Services
• Power of Attorney
• Representative Payee

http://www.kypa.net/drupal/?q=taxonomy/term/132
Letter of Intent

Documents a variety of important issues detailing what they want for the future of their loved one.

Update on an annual basis

Keep with family records
Quality of Life issues are those things that need to be in place for each of us to be comfortable in our daily lives.

<table>
<thead>
<tr>
<th>Where the person will live</th>
<th>Religious Affiliation</th>
<th>Continuing Education</th>
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<tbody>
<tr>
<td>Employment preferences</td>
<td>Social activities preferred</td>
<td>Medical care required</td>
</tr>
<tr>
<td>Behavior management practices</td>
<td>Medical care required</td>
<td>Social activities</td>
</tr>
<tr>
<td>Advocacy and guardianship needs</td>
<td>Trustees identified</td>
<td>Financial arrangements</td>
</tr>
<tr>
<td>Detailed instruction for everyday living activities</td>
<td>Communication</td>
<td></td>
</tr>
</tbody>
</table>
Funding

After 21, funding is no longer a right!
Medicaid Waivers

- Supports for Community Living (SCL)
- Michelle P Waiver
- Home and Community Based Waiver (HCB)
Choosing a Medicaid Waiver

Different waivers meet the needs of different families and individuals

Possible changes in insurance and possible “patient liability” or co-pay for services.
Other Funding Options

- Hart Supported Living Grant
- KY IMPACT
- Impact Plus
Social Security

When your son or daughter turns 18, they may re-apply for social security as an adult.
The Office of Vocational Rehabilitation provides initial funding to people with disabilities to obtain and retain suitable employment.

If you would like more information, talk with your son or daughter’s teacher, visit www.ovr.ky.gov or call (800) 372-7172 to find your local branch.
Building Skills for Competency and Success
Skills at home

*It’s never too early to teach the child skills they will need in the future.*

Regardless of ability, what’s important to teach children for the future?
Common Housing Options

- With parents in family home
- With other relative in family home
- Foster home
- Immediate Care Facility (ICF/MR)
- Nursing home
- Group home
- In own home, with support
- In own home, independently
Skills at Home

Doing chores at home builds work ethic, a sense of responsibility, and vocational skills for the future!

Support parents in encouraging skill development in their sons and daughters.
Skills at Home
Take an inventory!

• Hygiene
• Safety
• Cooking
• Basic cleaning and chores
• Laundry
• Grocery shopping
Skill Building

5 Year old - Choose dinner once a week.

8 - Chooses dinner once a week. Assists at the grocery store in selecting items.

10 - Chooses dinner, helps put together a list before going to the grocery. Helps prepare food items and clean up.

12 - Chooses dinner, grocery list, takes lead in preparing food, helps clean up.
Recommended Characteristics of Transition Practices

1. Implement positive behavior supports to address behavior challenges
2. Match IEP goals to the student and family’s vision for the future
3. Take advantage of inclusive experiences
4. Provide a variety of community based experiences
5. Assist in the coordination of ‘seamless’ transition to new resources and service providers in the community

Wehman (2009)
Transition Practices

1. Implement positive behavior supports to address behavior challenges

Research tells us the longer a person exhibits a behavior, the more difficult it is to change

Behavior challenges may limit the child’s participation in inclusive or community experiences!
Transition Practices

2. Match IEP goals to the student and family’s vision for the future

Everything learned in school should prepare the child for their future.
The closer you get to graduation, you need to re-evaluate your plan

Prioritize skill acquisition!
Consider using accommodations to get around hard to learn skills

<table>
<thead>
<tr>
<th>Skill</th>
<th>Accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counting money</td>
<td>Debit Card</td>
</tr>
<tr>
<td>Cleaning products</td>
<td>Non-toxic, all-purpose wipes</td>
</tr>
<tr>
<td>Cooking on a stove</td>
<td>George Foreman grill, microwave</td>
</tr>
</tbody>
</table>
Transition Practices
3. Take advantage of inclusive experiences

The best way to learn acceptable social skills is from peers!

More inclusive experiences may lead to greater community inclusion
Transition Practices

4. Provide a variety of community based experiences

The best place to learn skills is where you will need to use them!

Exposure to the community increases the child’s experience base, as well as the experience base of your community members.
Transition Practices

5. Assist in the coordination of ‘seamless’ transition to new resources and service providers in the community

Throughout the child’s high school career, build resources and relationships.

Don’t wait until May!
Choosing Providers

Families need to be proactive in choosing providers and services

• Talk with other consumers
• Talk with employees from the agency

Consider experience, training, caseload of staff, do they seem to care?
Make Employment a Priority

• That’s why we become educated (IDEA)
• More money!
• Greater sense of independence
• Integration in the community
Post-Secondary Education

Higher Education Act of 2009 states that an individual with a disability (including intellectual), otherwise qualified for admittance into a University, may NOT be discriminated against.
Post-Secondary Education Opportunities in KY

• SHEP Program through HDI, UK
• Kelly Autism Program at WKU
• Developmental Disabilities Clinic at EKU

Every University has a Disability Resource Center that can assist the child
Building Opportunities for Happiness and Well-being
Use special interests as a jumping off point for skill development, motivation, and friendship building
Questions to ask parents

What special interests does your child have?

Are there activities that your other children participate in?
Special Interest example

“As a young adult, some of the happiest days of my life were working in equipment design where I had to figure out how to design things.”

---Temple Grandin

Accomplished author, speaker, animal activist, and woman with ASD.
Don’t forget to encourage development of leisure skills or hobbies!

http://www.indiana.edu/~nca/leisureed/leisure.html
What about making friends?

Encourage parents to speak with teachers or counselors about students the child might be friends with.

As the child gets older, encourage participation in organizations associated with special interests.
Getting Older

As the child enters middle school, and moves on to high school, social situations may get more complicated!

Explicit instruction may be needed. Like any other skill, use evidence based practices to teach social skills.
Social narrative example

Taking a date to a dance can be fun! You can dance and hang out with your date. To get a date, you have to ask a person on the date and they have to say “Yes”! Lots of people are nervous that someone will say “No”. It’s okay to be nervous or sad if someone says “No”. You can say “Would you like to go to the dance with me?”. If the person says “No”, it’s okay. You can say back, “That’s okay, thanks!”. Then, you should walk away. There are lots of people you can ask to the dance. It will be fun to go with someone else!
Boyfriends and Girlfriends!

While people with ASD may have difficulties with social interactions, a romantic relationship/intimacy may still be desired.

Autism doesn’t affect hormone production!
Dave and Lindsey

• Both successful, professional adults diagnosed with ASD
• Met at an autism conference in 2005

“I’m so lucky to have found him,” she says. “When I’m with him, I forget about my challenges.”

Bringing it all together....

- Physiological needs
- Safety needs
- Belonging and love needs
- Esteem needs
- Self-actualization

Self Determination
Shoot for the moon. Even if you miss, you’ll land among the stars.


Questions?

Contact info:
Jennifer Bobo, LCSW
jlbobo02@louisville.edu

Center contact info:
Telephone: (502) 852-2467 or 800-334-8635 ext. 852-4631 Fax: (502) 852-7148 E-mail: katc@louisville.edu

https://louisville.edu/education/kyautismtraining
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