

# TRANSITION

## Notes-Slides

Reno, NV  
July 2003

# TRANSITION

From this...



To This...



Now What?

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## Transition

- If you are like me you may have spent some years fighting, crying, and hopefully even laughing while working with your school district to make sure the "appropriate" services were given to your child...
- Well now, those skills you learned during all those years of tears and laughter and will once again be used.

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## Some things we will talk about

- Getting Organized
- What to expect
- Ask, Ask, Ask
- Employment
- Schooling-Higher Education
- SSI
- Insurance
- Independent living

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## Get Organized

- Make sure you have a BIG binder to keep all your information in.
- Keep names and phone numbers handy
  - There are lots of different agencies. Lots of different people, it's like building a team. At first it may even be hard to keep track of who works for which agency and where they get their funding from.
  - Name and number sample sheet in packet
  - I taped it on the inside flap of the binder
- Be patient it does take time...But call back if they don't call you back.

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## Get Organized *cont.*

- Before they graduate from high school make sure they have a current Multi Factor Evaluation. (*MFE*)
- Normally these are done for free every 3 years by the school district...private ones are also available at YOUR cost.

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## Get Organized *cont.*

- Have an official, yet understandable explanation of Galactosemia.
  - I still think PGC's explanation is one of the most understandable...*Galactosemia is a rare inherited metabolic disorder...whereby the individual is "missing" the enzyme to convert galactose...The accumulation of galactose is like a poison to the body that can cause complications...*
  - You may want to also have an "official" explanation...maybe even use some of the literature that makes things sound a bit more desperate...
    - Some examples that I have used are in your packet.

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**Get Organized** *cont.*

- Find your most recent IQ tests
- Also find the Lowest IQ test they have ever had...

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**Get Organized** *cont.*

- Start calling and asking
  - Call your State Department of Disabilities.
  - Call your County Department of Disabilities
    - They are also sometimes called the Department of Mental Health
  - Nobody will offer anything, YOU have to ask!

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**What to expect**

- Good news! "Adult Supportive Services" is much more of a positive team effort than what you may have worked with at the school level.
  - After all, the state and county wants these individuals to become happy, working, independent adults just as we parents do.

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**What to expect** *cont.*

- Once again you will be starting at square one...explaining what Galactosemia is and NO they will NOT out grow it!
- There may be more evaluations
  - Our experience has been very positive however. They used the schools MFE, the IQ test I sent them.
- Lots of paper work to get the ball rolling

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**What to expect** *cont.*

- An IQ of 70 or less will open many doors...*Don't panic...you and I know these IQ tests are not the true readings of our kids intelligence or abilities...but the State thinks they are...so go with it!*

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**What to expect** *cont*

- For Ohio's eligibility there was a brief questionnaire that was done in our home. It only took about an hour.
- There needed to be a double diagnosis...Galactosemia certainly qualified as one. Then for the second there needed to be a deficient in 3 or more of the 7 life skill areas.

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### What to expect *cont.*

- The 7 life skill areas are.
  - Mobility
  - Receptive and expressive language
  - Self-care
  - Self-direction
  - Capacity for Independent living
  - Learning
  - Economic Self-Sufficiency

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### What to expect Once qualified for services

- Individual Support Agreement (ISA)
  - This is similar to an IEP*
  - The ISA is done on a yearly bases.
  - Can be amended at any time.
  - Is where you ask for the funding for the the services you are requesting.
  - Can cover everything from additional schooling, to work, to transportation reimbursement, to social activities, etc.

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### ASK, ASK, ASK

- Have your questions *priorities* in mind.
  - Is your first concern employment?
  - Further education?
  - Transportation?
  - SSI?
  - Medical Insurance?
  - Independent living?

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## ASK, ASK, ASK

- Keep asking.
- Remember they won't **OFFER** anything to you, you have to **ASK**.

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## Schooling – Higher Education

- Technical and vocational colleges are huge right now!
  - Admission fees and tests are minimal
- Community colleges as well as Universities have resources, tutors, special needs counselors and supportive services for people with learning disabilities just like school did.

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## Employment

- There are agencies that have funding for things like
  - Job coaches
  - Job developers
  - Temporary and/or job "try-outs"

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## Transportation

- Driving lessons or evaluation
- If not driving, reimbursement of your mileage to and from doctors, work, school, etc.
  - Sample letter and mileage log in packet
- OR reimbursement to hire a driver?
  - The key here is finding reliable and dependable people

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## SSI

- Again based on IQ
- Questions can be answered by phone
- Can't have more than \$2000 in their name
  - Requires monthly maintenance
    - Example of a monthly letter is in your packet
    - Amount received monthly, if any, is based on monthly wages.
    - Keeps them in the system even if there really isn't a monthly check because they make too much money at their job.

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## Insurance

- Know your Health Plan from work
  - Most have a clause that states if they are permanently disabled then the usual age or full time student restrictions do not apply.
  - Again be sure to read and ask. Don't just assume you HR department knows the correct answer...first denied...try, try again.

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### Insurance *cont.*

- Don't forget about Medicaid
  - There are monetary restrictions...*usually can't have more than \$1500 in the individual's bank accounts.*
  - If they are receiving SSI they should also qualify for Medicaid.

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### Independent Living

- Some states have still have the "group home" concept.
  - Not great for individuals with special diets
- Again ASK, they also have funding to subsidize the individuals rent depending on their income.
  - They may be able to live in what ever apartment they choose and have the county subsidize their rent.

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### Independent living *cont.*

- Get needs and services written into the ISA
- Request funding for specific needs
  - Help with Grocery shopping?
  - Preparation of meals?
  - Paying bills?
  - Cleaning?

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Independent living *cont.*

Again, the funding may be available... it's a matter of finding and hiring dependable, reliable, honest people!

**Interview and  
check references!!!**

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Independent Living *cont.*

- Remember in this day and age most everyone's kids move in and out several times! Regardless of their abilities.
- Build and plan for success but why expect MORE...life is a journey full of peaks and valleys for **everyone!**

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We really have been blessed

- As parents I feel it's our job to help them reach their full potential...to make sure they have the right services and supports in place.
- But it is also equally as important to remember in order for them to reach their full potential...we also have to let go.

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### We really have been blessed

- What ever their abilities they do grow up into kind, compassionate adults!
- They lead full lives that touch everyone's lives around them in ways we never even knew were possible.

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Remember to relax and enjoy each stage along the way



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