

When the Bus Stops Coming!



Goal for Today



- To help families that have sons or daughters to actively participate in the transition process

After This Workshop, You Should Be Able To:

- identify basic resources available in the community
- list personal resources and skills you are committed to sharing with others
- identify key individuals or agencies where cooperation is critical for success
- identify appropriate waiting lists and plan accordingly
- have a better understanding of the Medicaid Waiver
- be able to identify the preferences/strengths and support needs for your child and plan accordingly, and
- realize that resources may not ever match up to the support needs
- accept a level of responsibility for coordinating services

What's Really Important To Us?

About Health

How We Spend Our Time

At Home

MY DREAMS

Resources

Relationships

Values

VALUES & PHILOSOPHY

SELF DETERMINATION:

“Acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference.”

Beach Center on Families and Disabilities

TYPES OF SELF DETERMINATION SKILLS:

- making daily choices
- communication
- making decisions
- problem solving
- setting goals
- personal responsibility
- self-evaluation
- self-awareness

VALUES & PHILOSOPHY

SELF ADVOCACY MEANS:

SPEAKING AND ACTING FOR
ONESELF BY:

- learning new skills
- having true life experiences
- making informed decisions

Self Advocacy is essential to
improve quality of life

- all people should be encouraged to make decisions
- increases self-esteem & self-worth
- use abilities to control their own lives
- to be treated with dignity and respect as one would treat anyone else
- having access to assistive technology, personal assistance and other supports to be able to speak and do for themselves

VALUES & PHILOSOPHY

SELF EMPOWERMENT

Empowerment means assisting individuals to learn to make choices, creating an environment in which those choices will be honored, and giving individuals and families control of resources

Minnesota Governor's Planning Council on Developmental Disabilities (1991)

LONG TERM OUTCOMES

CONQUER AND REPLACE:

- hopelessness with hope
- superimposed passivity with dignity of risk
- joblessness with a real job at a real wage
- inaccessibility with true access
- speechlessness with meaningful expression
- confusion resentment and anger with real choice
 - apathy with activism
- darkness at the end of the tunnel with light

Williams, (1989). In *Leadership for empowerment*

What is Transition and Why is it so Important?



WHAT IS TRANSITION ?

Webster's Definition:

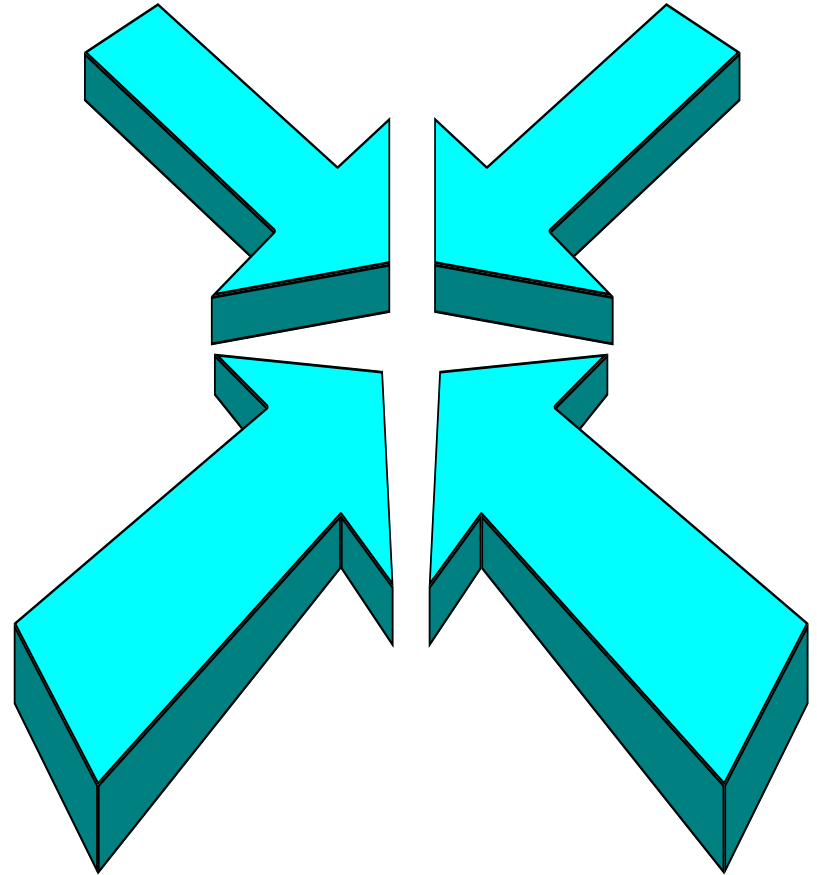
- passage from one state, stage, subject or place to another.
- movement, development or evolution from one form, state, stage or style to another

FOR US TRANSITION MEANS.....

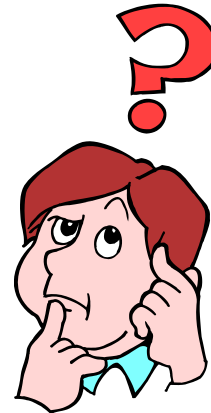
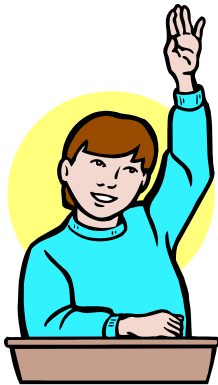
- movement from school to school and from school to adult life
- preparing for employment, living, and participating in the community
- parents and students should take an active part in transition planning and understand their responsibility

THE PHILOSOPHY OF TRANSITION

- recognize that student and parent are critical in the process
- planning, planning, planning....
- develop skills to make informed decisions
- share responsibilities and overcome hurdles
- students with disabilities should have high expectations and valued roles in our community



What age do we start?



STUDENT AND PARENT ROLES

Age 14-16

- develop IEP transition goals that includes self-awareness, job training and independent living
- research adult services-how, when and why to access them
- get on waiting lists
- are you working towards an IEP or regular diploma



AGE 16-18

- magic age of majority (18). Register to vote and the selective service (men)
- make referrals to appropriate agencies (DRS, CSB, SSA, DSS/Medicaid)
- involve adult service providers in transition planning
- increase student involvement in transition planning and decisions
- consider functional assessments to develop employment, living & community needs
- discuss issues related to self-advocacy & empowerment
- discuss guardianship and develop alternate plans

AGE 18 - 21



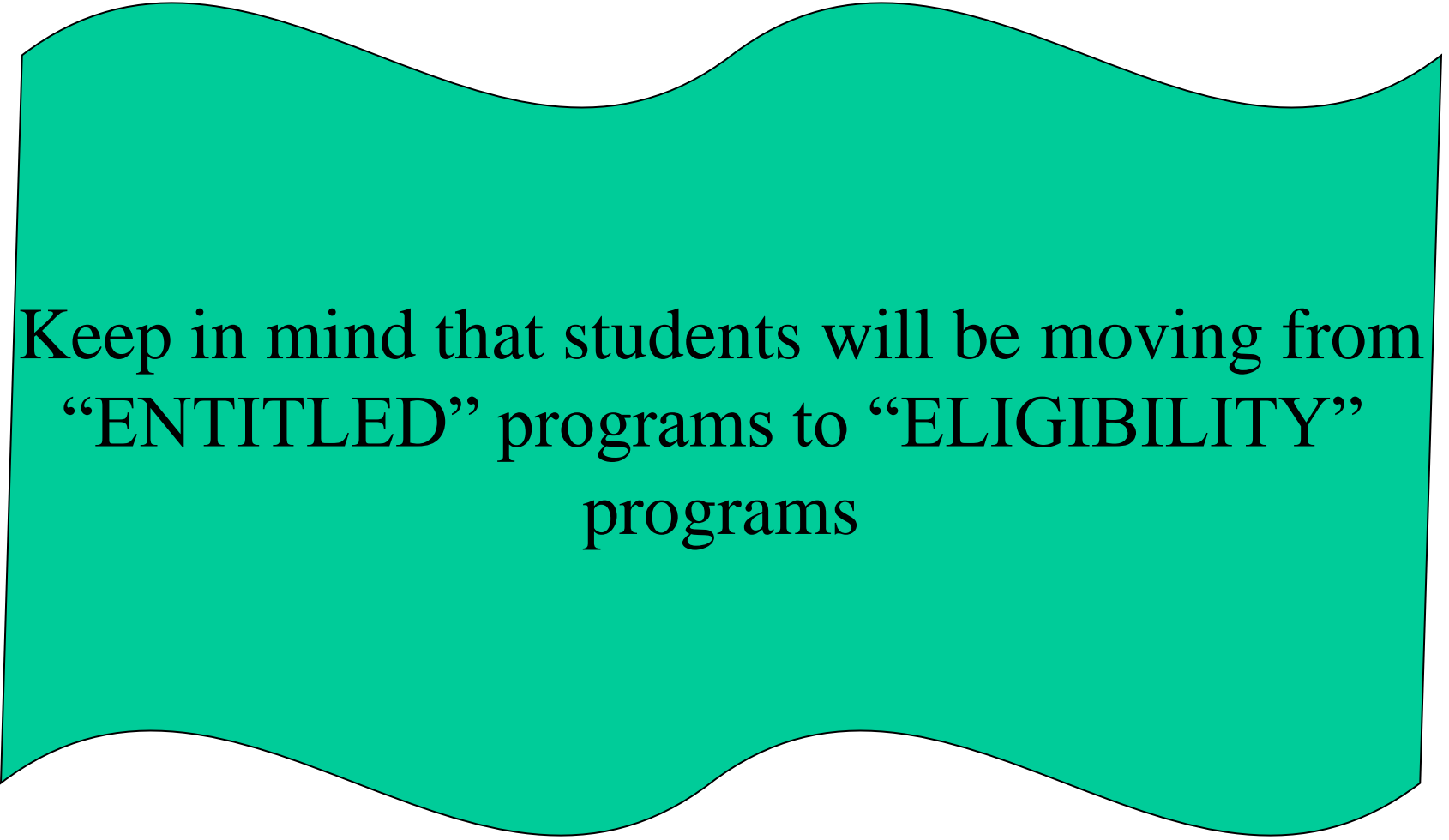
- begin to implement & finalize transition plan
- visit adult service provider sites
- review goals and identify supports
- consider PT employment (DRS/SE)
- encourage greater personal independence and personal care
- provide support in establishing appropriate living arrangements and community activities

Turning 22...

Is the beginning of the
rest of your life.

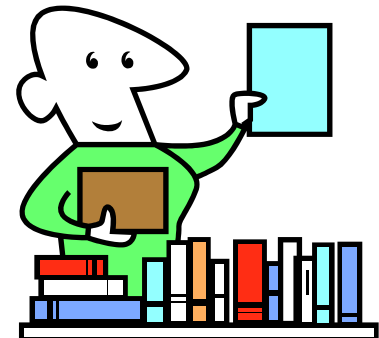
Everything will change,
nothing will be the
same, and you will
survive.





Keep in mind that students will be moving from
“ENTITLED” programs to “ELIGIBILITY”
programs

Do I really need to keep all these records?



The Importance of Keeping Records

- before leaving school, gather a record of all relevant reports (transcripts, evaluations)
- keep records of work experience and request letters of recommendations from prior employers
- keep accurate notes of all telephone conversations with agency staff
- record each conversation and keep conversations with one agency together in a file
- have file folders handy to keep brochures or handouts you are given
- always keep a copy of any letters you write to an agency
- periodically go through your records to refresh your memory and address pending issues

How Should Parents be Involved in Transition Planning?



Parents Desire for Involvement...

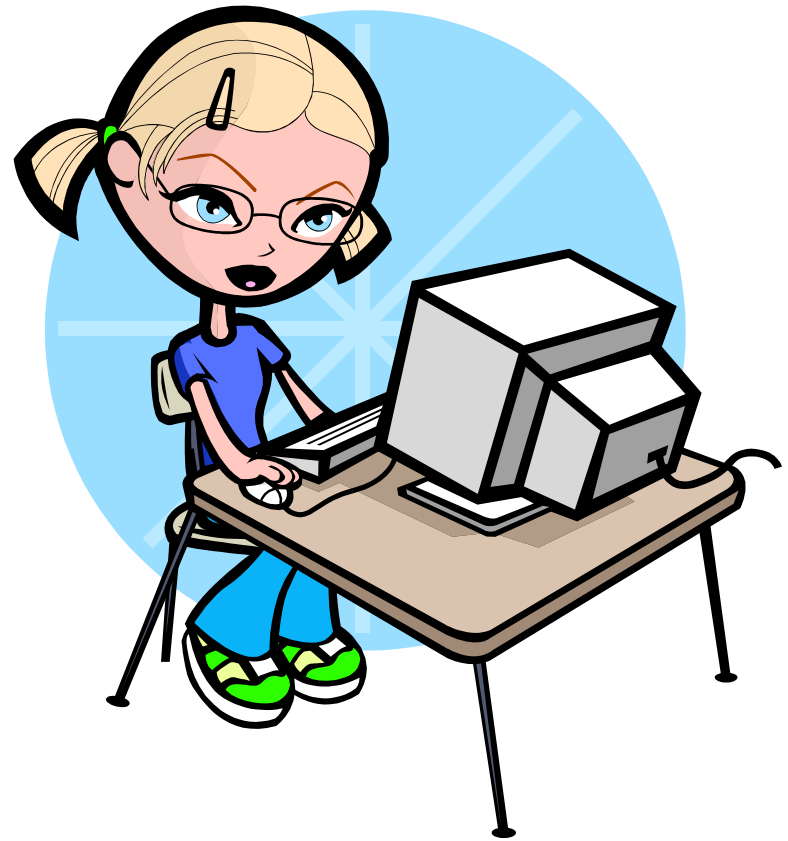
A Survey of 200 families found that parents were significantly less involved in the transition process than they desired...

- nearly 70% desired involvement, but slightly more than 30% experienced involvement
- significantly more parents desired to have an equal part in the decision making than were given the opportunity
- although 12% indicated no involvement experience with the transition team, < than 2% indicated they desired no involvement
- parents wanted to be involved in finding job placements and community living arrangements more often than they had the opportunity to do so

What Could This Mean?

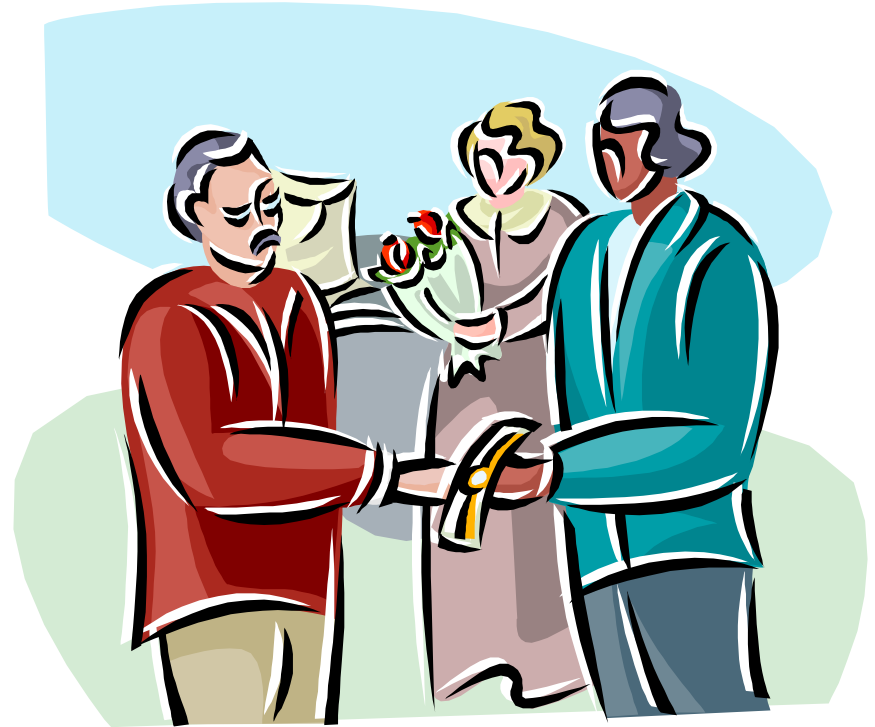
“Lack of parent participation and involvement may be detrimental to the achievement of successful transition outcomes.”

(Johnson & Rusch 1993)

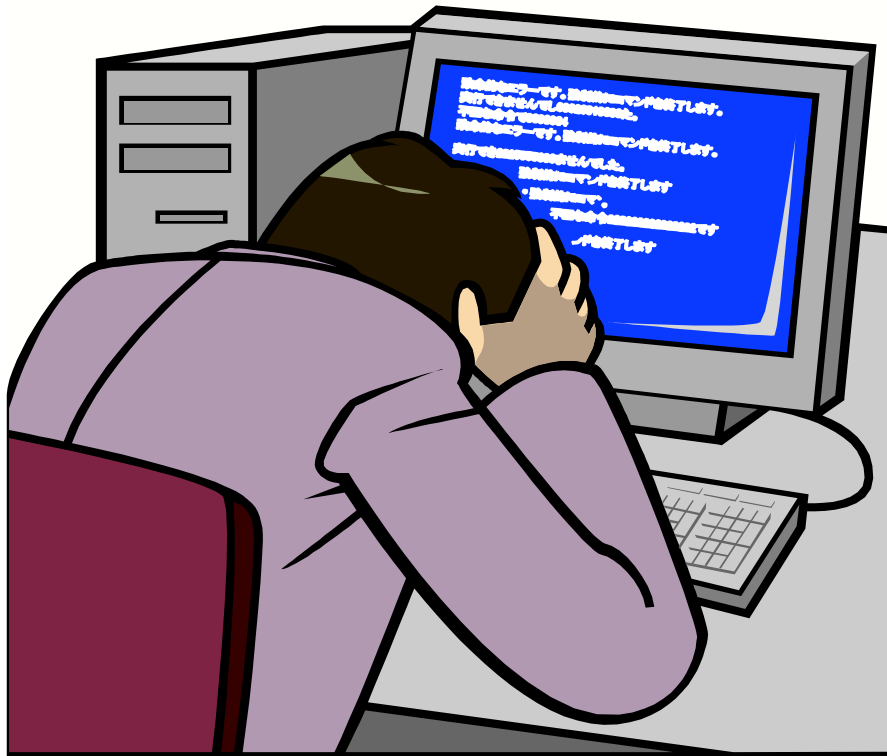


Why Should Parents Be Involved?

- parents know their children better than anyone else
- parents can be effective in maintaining continuity of training and purpose
- parents can act as system advocates and facilitate changes that professionals are constrained to accomplish



After High School, What's Next?



“Don’t be afraid to take a big step if one is indicated. You can’t cross a chasm in two small steps.”

David Lloyd George

Sometimes, big things require big steps and they require risk.

The Transition Checklist

This is not a test!

It is an opportunity to see the skills and strengths your child has and what areas may be overlooked.

Vocational Skills



Can he/she:

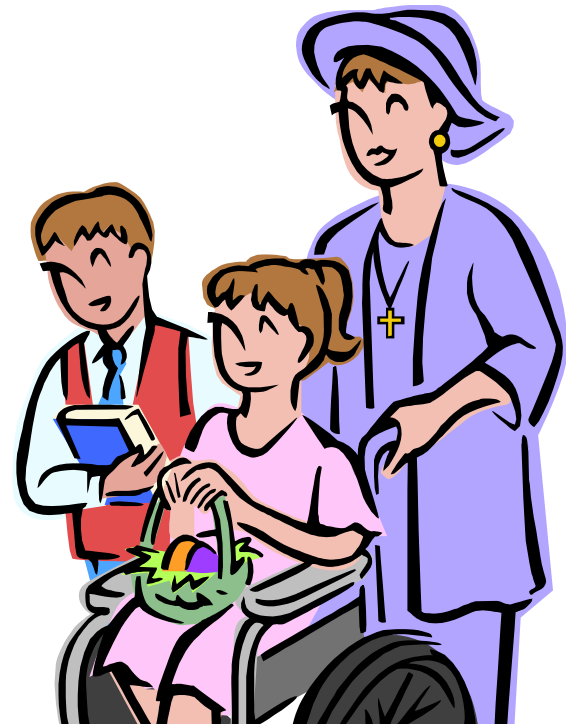
- Get to/from work on time
- Punch in/out properly
- Work cooperatively with others
- Take lunch/breaks appropriately
- Wear suitable clothing
- Use appropriate safety procedures
- Follow directions
- Accept supervision

Working



- Adults work
- Most teenagers work, too
- Even some pre-teens work
- People with disabilities can/should work....somewhere
- In competitive jobs in the community
- In an enclave or group setting
- Volunteer, or
- Day support service not focused on employment, or
- A medically fragile program

Developing a Social Network



The Social Network

- Having something to do and someone to do it with
- Loss of school activities can be hard to replicate
- TV can become a time consuming friend
- You will need to seek out community and specialty social activities



Social/Personal Skill

Can he/she:

- Supply appropriate personal identification
- Greet people appropriately
- Use contemporary style of dress, hair
- Use good grooming, hygiene skills
- “Talk” with friends/co-workers
- Be courteous
- Be responsible
- Be happy



Community Skills

Can he/she:

- Use public transportation
- Shop for groceries/clothing
- Make necessary appointments
- Use the phone
- Use bank accounts
- Be safe in traffic, among strangers
- Know how to seek help
- Handle their money



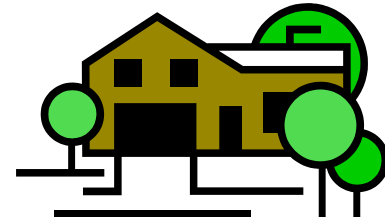
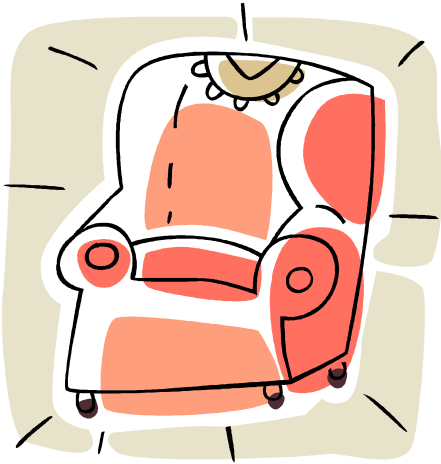
Recreation and Leisure



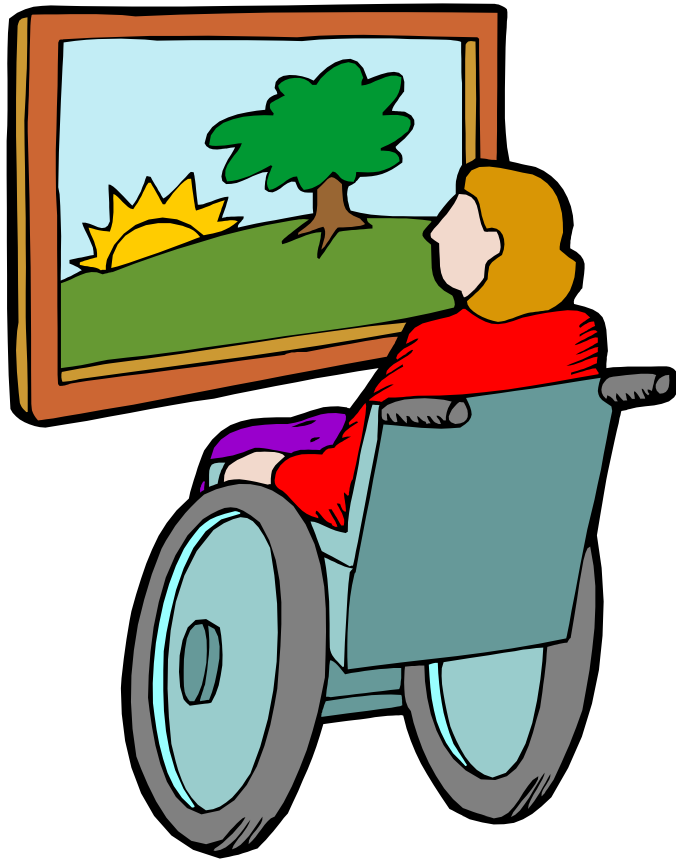
Can he/she:

- Use free time for pleasure by choosing reasonable activities
- Pick a hobby
- Perform required activities
- Use community resources

Where are they going to live?



Community Living



- Personally owned home or living with family
- Vendor owned home or apartment
- Group home/waiting list
- Section 8/waiting list apartment/home
- Adult foster care
- Supported Living/waiting list
- Adult Care Residences
- Homelessness

Living



- Be aware of group homes
- They are not always the pot of gold at the end of the rainbow
- They can make you very happy, but also can let you down

How we gonna pay for these things?



Sources of income/funding

- Wages
- SSI/SSDI
- State/local funding
- Family contributions
- Section 8 (CLOSED WAITING LIST)
- Food Stamps
- Medicaid/Medicaid Waiver (some waiting lists)
- Personal Care Attendant Programs
- Wills/Trusts/Estate Planning
- Consider saving money for future services, like their college education



Income

- SSI does guarantee a monthly income
- **HOWEVER, IT DOES NOT GUARANTEE SELF-RESPECT!**



Estate Planning – A Parent's Suggestion

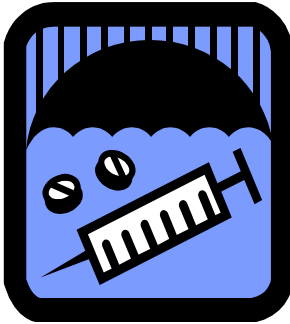
Carol and her husband recently completed their estate plan so that their children would be provided for. They have twin sons who do not have disabilities and a son with Down syndrome. Here is what Carol has to say about the process of estate planning:

When my husband and I went to talk to the lawyer, we hadn't really talked much about ourselves first. I thought that since we agreed on almost everything about caring for Frank, our son with Down syndrome, we would be in agreement about how to provide for his future needs, when we weren't around anymore to care and advocate for him.

We found out, though, that we had different ideas. And we found out in the lawyer's office! Then we got home and found out our twins were hurt that we hadn't consulted them at all, had just assumed they wouldn't want to be responsible for helping Frank when we were gone. So then we did what we should have done before going to see the lawyer – we talked as a family.

So my advice to other parents is: *Before going to the lawyer for the first time, talk among yourselves about the future and your ideas for how to provide for your son or daughter with a disability. Then talk to the lawyer. Then return home for more discussion within the family. Then continue working with your lawyer and financial planner to create a plan the family can feel comfortable with.*

What About Health Insurance?



Medical Insurance



- family policy until a certain age
- employer health benefits
- Medicaid
- secondary insurance carrier

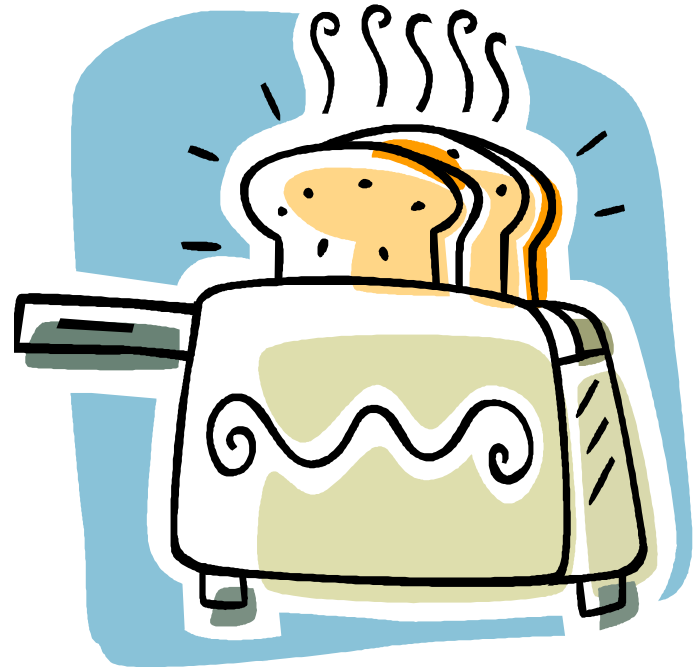
What about domestic/personal care needs?



Domestic Skills

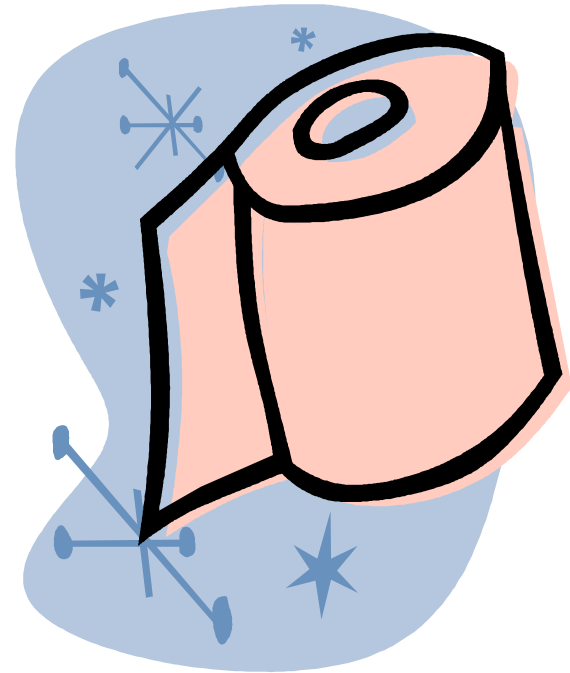
Can he/she:

- Prepare a breakfast, lunch, supper, snack or pack a lunch
- Clean their own room
- Do laundry, use the washer/dryer or iron
- Budget their time

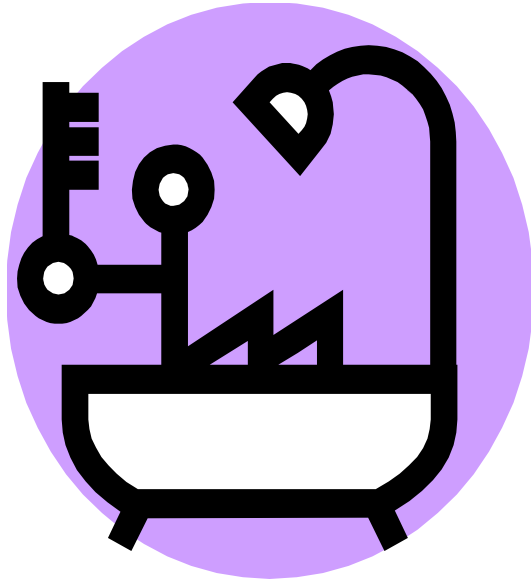


Personal Care

- Teach your children how to use the bathroom-by themselves
- Resist the temptation to wipe them when they should be doing it themselves



Personal Care



- Make sure they know how to shower-alone
- Not a group activity
- Make sure they know this is a daily activity
- Make this a rule
- No exception to the rule!

Personal Care

- Wearing clean clothes is essential
- Changing them every day is important
- Teach them how to do laundry
- Show them stains on their clothes and not to wear clothes with stains



Sleeping

- Just a reminder that daytime is for being awake
- Night time is for sleeping
- Some people just don't understand this concept

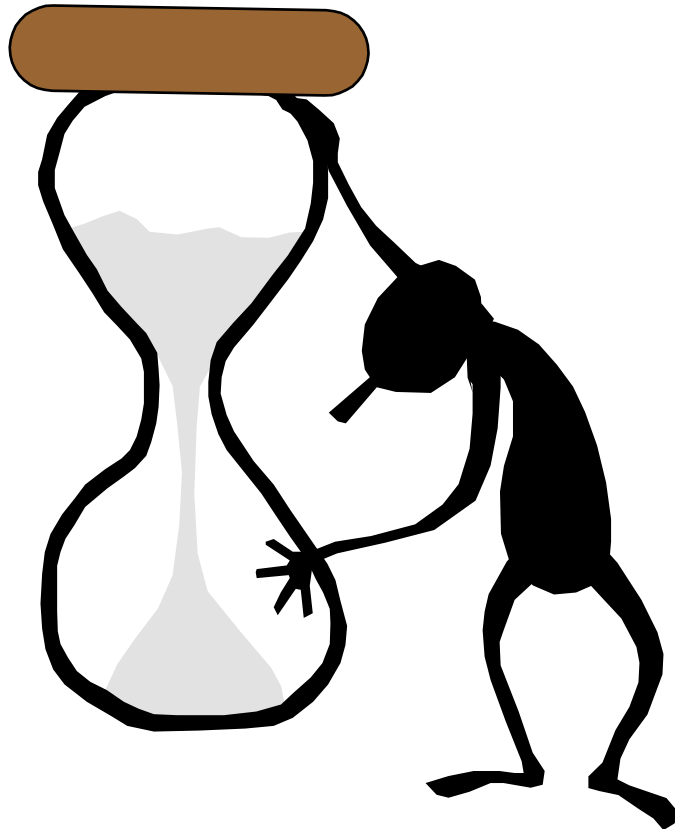


Learning

- Do not let anyone tell you that your child cannot learn or even read
- Learning does not end!



Respect



- We all want it!
- We want our kids to receive it, but must also be willing to give it
- Means doing what the boss tells you to do whoever the boss may be

Mistakes



- Don't blame someone else for mistakes
- This can set a bad example
- Mistakes are inevitable
- Move on!

Family

- Don't expect siblings to be the parents
- Brothers and sisters want information — lots of it
- That's not the same thing as wanting responsibility



Finally....



- If you don't teach your child to cross the street, they will never know what's on the other side, and...
- Neither will you!

People with disabilities want to
boldly go where everybody else
has already been

~Bumper sticker, VW Van, Greenwich,
Conn.

Depressing Statistics.....



Virginia Statistics

- 38th for “best” Medicaid services for individuals with intellectual and developmental disabilities
- 41st for allocating resources to those in the community (non-ICF-MR)
- 15th for supporting individuals in the community and home-like settings
- 47th for keeping families together through family support (people living at home)
- 14th for supporting meaningful work
- States Ranking of Medicaid for Americans with Intellectual and Developmental Disabilities:

Year	2011	2010	2009	2008	2007
Virginia	38	42	41	47	45

What is a Medicaid Waiver?



Available Waivers in Virginia:

- Intellectual Disability Waiver (MR)
- Alzheimer's Waiver
- Elderly and Disabled Waiver (ED/CD)
- Individual and Family Developmental Disabilities Support Waiver (DD)
- Technology Assistance Waiver (TA)
- Aids Waiver
- Day Support Waiver

- Disability is a natural part of the human existence and in no way diminishes the right of persons with developmental disabilities to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.”

– The Developmental Disabilities Assistance and Bill of Rights Act Amendment of 1993

QUESTIONS OR COMMENTS?

Contact the Parent Resource Center for additional information

Contact Information - Loudoun CSB

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