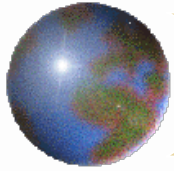


*Other Things Leaders Need to Think About:  
Beyond Demographic and Economic Realities*

**Ohio Association of County Boards of MR/DD  
Convention**

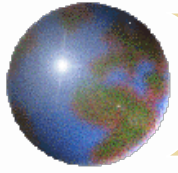
**Oct. 27, 2008**

***Nancy Thaler***



# *Topics*

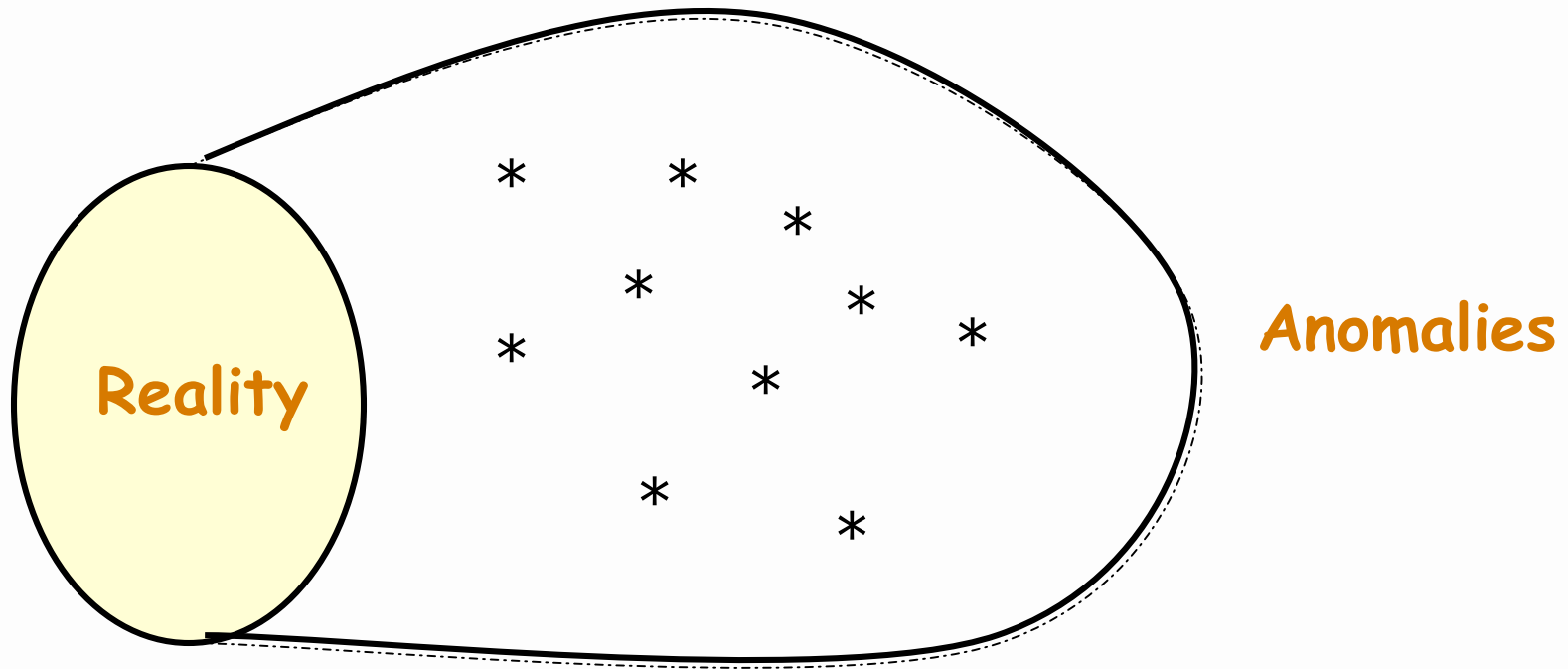
- Paradigm Shifts
- Person-Centered
- Diagnoses
- Quality
- Long Term Care Reform

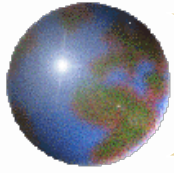


# *Paradigms*

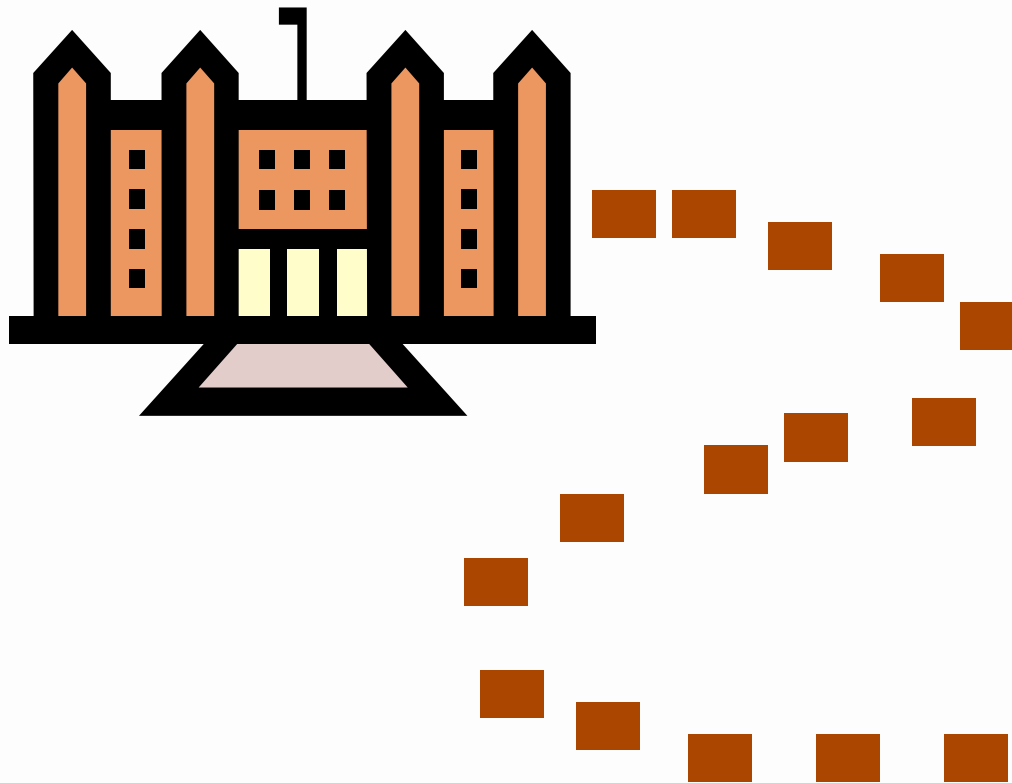
*The Structure of Scientific Revolutions*

*Thomas Kuhn 1962*

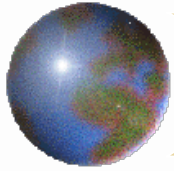




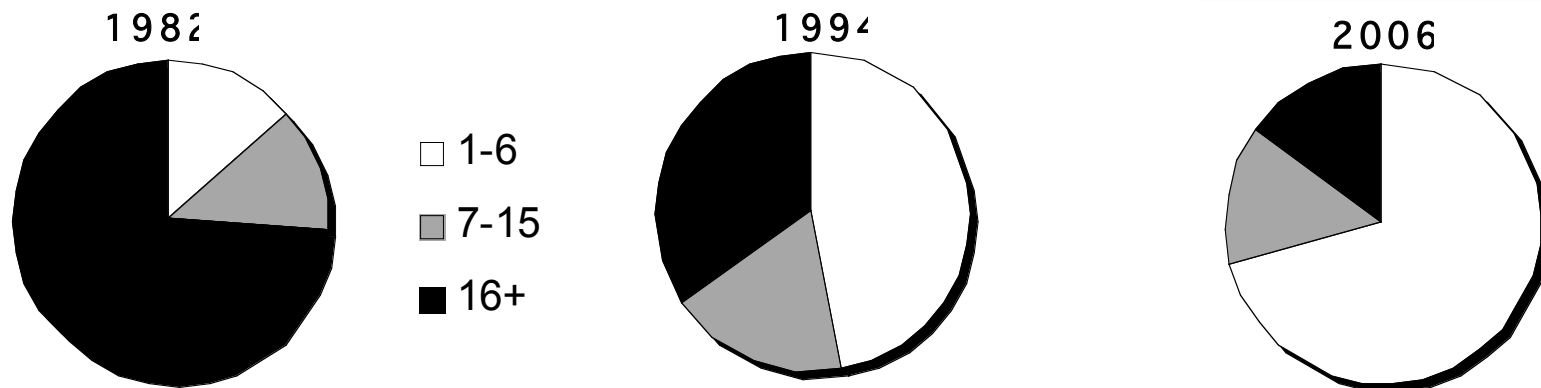
## ❖ *Where and with whom people Live*



**10 States Have No Institutions**



# Home Sizes Getting Smaller 1982, 1994 and 2006

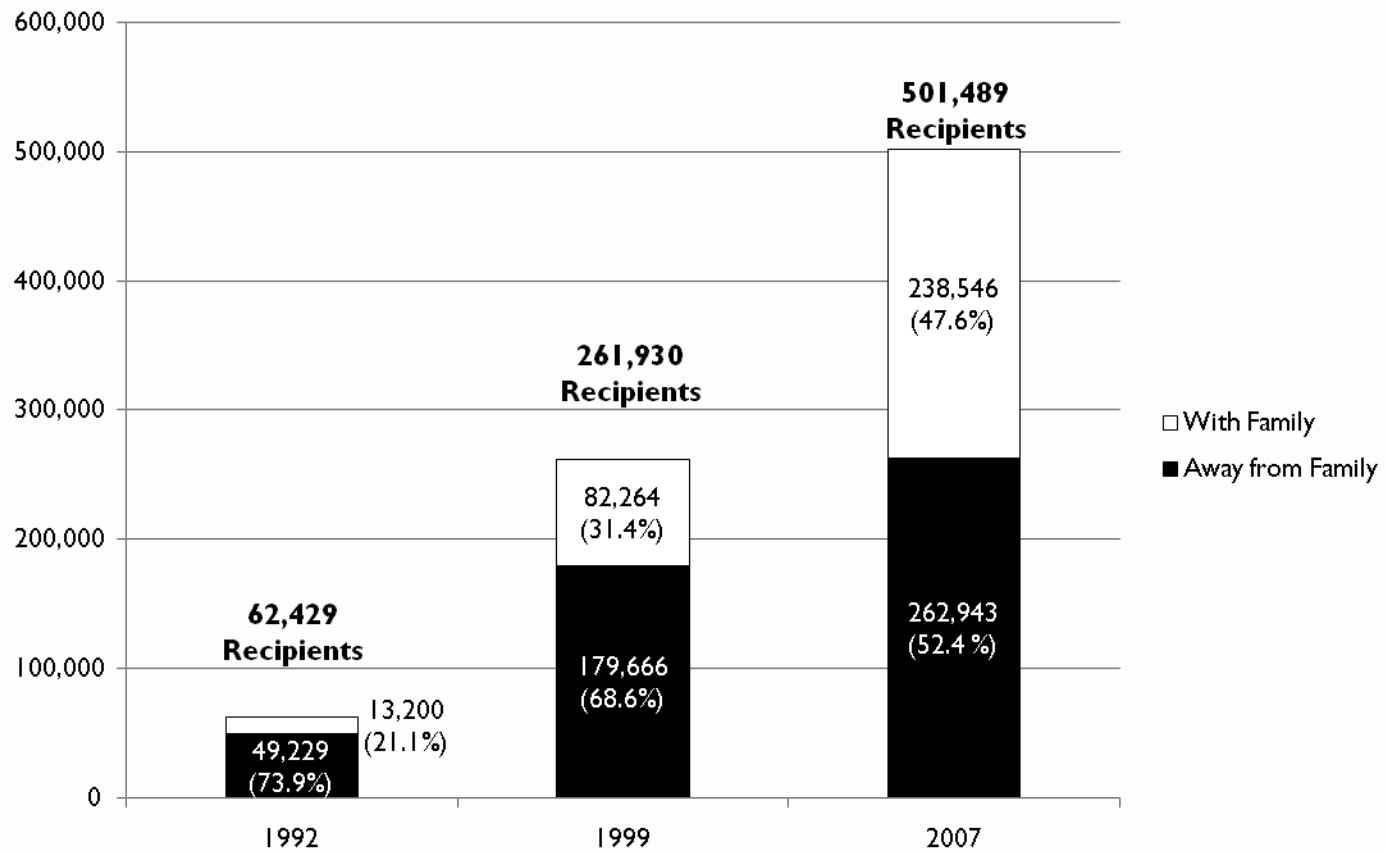


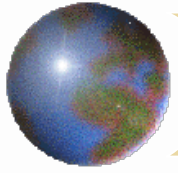
Vt. Has no licensed homes

RISP Report 2007, Prouty & Lakin



# *HCBS Recipients with Developmental Disabilities Living With and Away From Other Family Members, June 1992-2007*

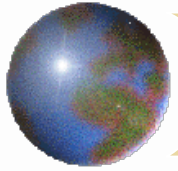




## *We Must Understand...*



- People live in the context of family
- Personal outcomes will be influenced by family
- Families aren't perfect
- Families need information and support
- Involvement in family dynamics is inevitable
- People need to work and have friends - and their family needs them to have that too

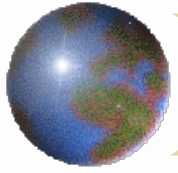


# *What We Have to Do*

- ✿ Keep the individual's identity and personal preferences primary

## Support Coordinators

- ✿ Plan for the person and the family...the earlier the better
  - ✿ Must be trained in family dynamics
  - ✿ Need support and supervision
- 
- ✿ Create opportunities for the person with a disability outside the family...get people jobs and support self advocacy

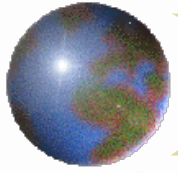


## ❖ *Person-centered*



- ❖ We've had IEPs and IHPs
- ❖ Self determination is the goal of ICFs/MR
- ❖ Why do we have to talk about being Person-centered ?
- ❖ Money is not unlimited ..must be conscious about it

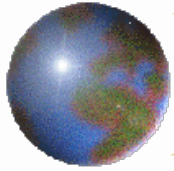




# *It's Not So Easy*



- We have to ask people about everything - no decisions about them without them
- Their decisions & preferences require us to do things that are hard
- Risk taking requires us to think and behave differently
- We are drawn into family dynamics
- It takes A LOT OF TIME
- Money no longer controlled by providers
- Requires more complex strategies in order to listen to the person and meet the assurances



# Building Person-Centered Organizations: Fulfilling the Promise of Person Centered Planning - *A Real Choices System Change Grant*

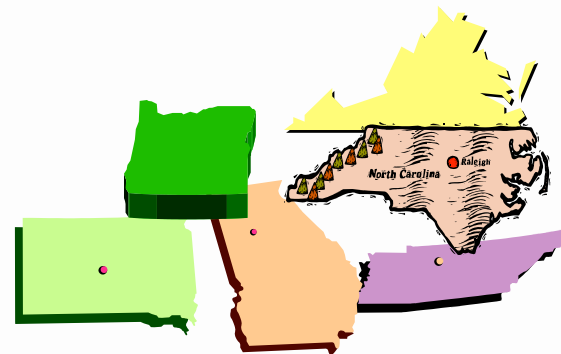
• \$2.1M for three years

• Six States:

Virginia  
Oregon

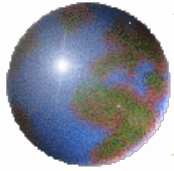
Georgia  
Tennessee

North Carolina  
South Dakota



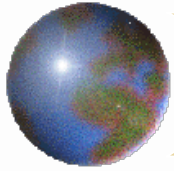
• Partners

- Michael Smull
- Nat. Assoc. State Directors of DD Services
- Virginia Commonwealth University Center for Excellence



# Three Levels of Change

- *Level One:* changes in **day to day practice** that impact persons' lives and their relationships with formal and informal supports;
- *Level Two* changes in **provider agency management and leadership** affecting organizational policy, practice, and program outcomes;
- *Level Three* changes in service delivery **system infrastructure statewide** resulting from changes in regulation, state policy and system design.

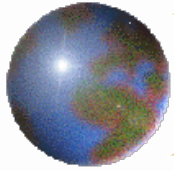


## ❖ *Diagnoses vs. Labels: Understanding the Difference*



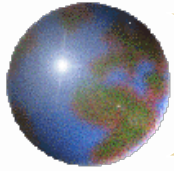
### ❖ Intellectual Disability/Developmental Disability definitions

- ❑ ID - Limitations in major life areas
- ❑ ID - Intellectual performance 2 or more standard deviations below average
- ❑ DD - limitations derived from either mental or physical impairments
- ❑ Both - evident in the developmental period



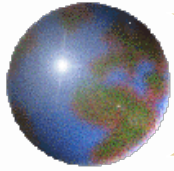
## *ID/DD - What Does it Tell Us About hat People Need?*

- **Need Accommodations**
- **Benefit from Training**
- **Need Support not Treatment**
- **Do not Expect Change in the Condition**



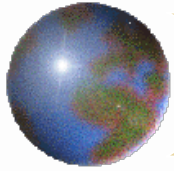
# *Learning about Autism*

- Autism is a behaviorally defined disorder characterized by
  - impaired social interaction,
  - delayed and disordered language and
  - isolated areas of interest
- The disorder is also accompanied by illnesses such as seizures, sleep disorders, gastrointestinal disorders, metabolic disorders, mental health disorders (OCD; anxiety; etc.), dietary intolerances, hormonal imbalances



# *Learning From Autism*

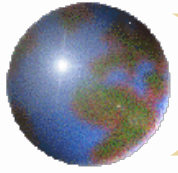
- Autism Spectrum - Autism is not one singular disorder but there are many "autisms" which manifest differently in individuals and respond differently to interventions
  
- Autism
  - Is not only an inherited disorder;
  - Environmental factors contribute to its incidence
  - Modifications to the environment, dietary interventions, detoxification strategies, and other treatments may contribute to amelioration and recovery.
  
- Rhett's, Down and Fragile X Syndromes are now understood as being co-morbid conditions with autism



# *Autism: What Does it Tell Us About What People Need?*

- Treatment for physical and mental health problems Gastro intestinal disorders; metabolic/hormone treatments; sleep disorders; OCD; anxiety; depression; Bi-polar disorder; post traumatic stress
- Teaching and training as early as possible
- Accommodations - full spectrum lights; sound modifications; special diets; adjusted activity schedules; physical proximity; communication supports
- Support services are important
  - Time to engage in special interests; personal assistance; transportation; companion; facilitated communication

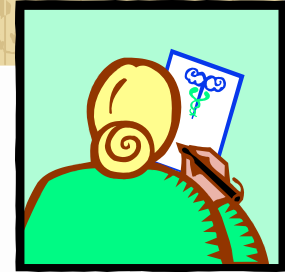
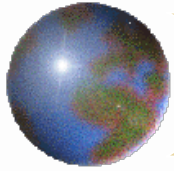




# *Did We Throw the Baby Out with the Medical Model?*

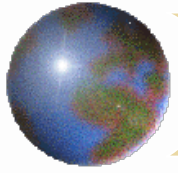


In rejecting the medical model and embracing the developmental model, we may now be missing information that would be useful in making people's lives better.

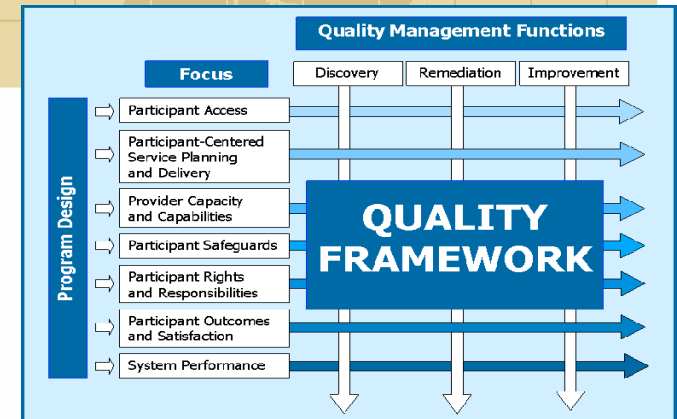


## *Pay Attention to Diagnoses*

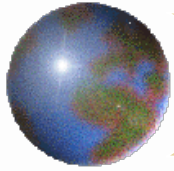
- Alert us to physical and mental health problems that should be treated
- Indicate types of treatment and support that will be helpful
- People will likely have more than one diagnosis including health conditions, mental health conditions as well as disability related conditions



# ❖ Quality - More Than Ever

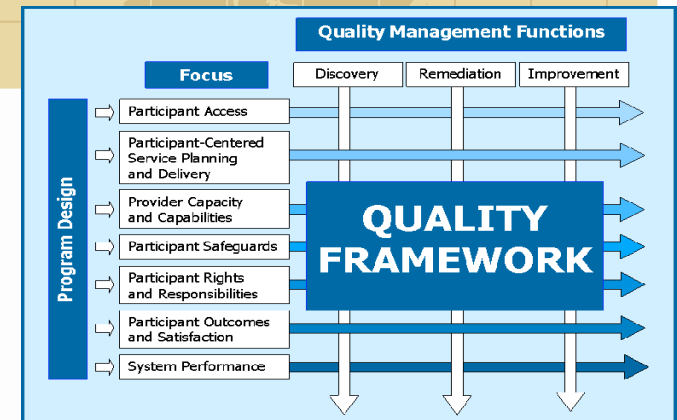


- 300 + Waivers
- 1,000,000 people getting services
- \$25 Billion; 36% of LTC budget and growing rapidly
- GAO study of states' review of deaths
- Pay for Performance
- Hospital Med. Errors as a Public Health Issue
- DRA requirement to develop quality measures
- CMS 1915 C waiver expectations for Quality
- Because we can know, we have to know

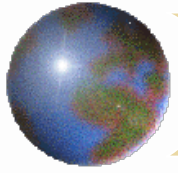


# ❖ Quality

Quality Can't be **Assured**  
or **Improved** without.....



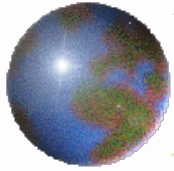
- Real Infrastructure
- Information Technology



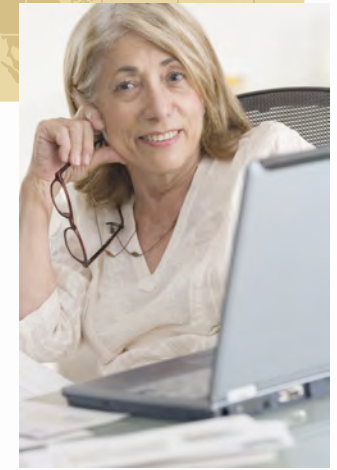
# Infrastructure is as Important as Service



- Strong case management system
- Real provider development and provider management
- Information Technology
  - People who can turn data into information
  - People who will use the information to remediate and improve

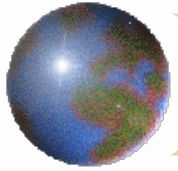


# Case Management



- Free from Service Provision
- Caseloads appropriate to need
- Training in human development; family dynamics; social justice
- Professional/Clinical Supervision
- Authority to act on behalf of the person

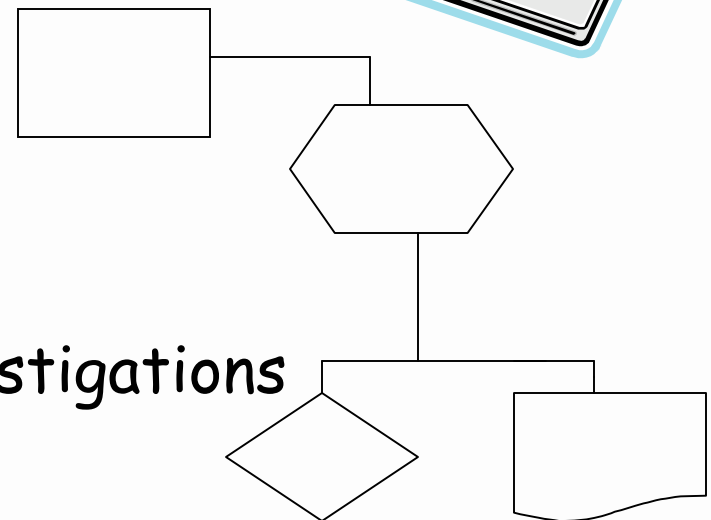


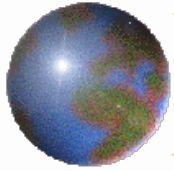


## *I.T. - It's About Managing Work Flow*

✿ It is basic infrastructure to manage work flow to make sure it gets done right

- ✿ Intake and assessment
- ✿ Develop and monitor the plan
- ✿ Service Authorization
- ✿ Financial management
  - Individual budgeting
  - Payments/Fraud and Abuse
  - Planning and Budgeting
- ✿ Managing Incidents and Investigations

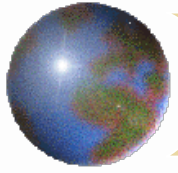




## *I.T. = Big*



- CMS needs to actively support the development of I.T....90% match for development
- State DD agencies need to make the business case for I.T. investment to their budget offices
- 40 - 60 % of Gov't I.T. projects fail: find out why

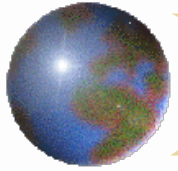


# *Long Term Care Reform*

✿ Why? Save money and improve care

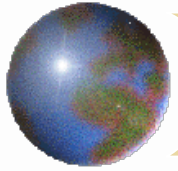
✿ How?

- Consolidation of agencies and programs
- Consolidation of common agency practices
- Assigning responsibility to contracted entities - MCOs; SNPs



# *LTC Reform - Danger and Opportunity*

- The DRA 2006 even more options for states to craft their programs
  - 1115;
  - 1915(b);(c);(b-c);
  - 1915(i);
  - 1915(j);
  - Special Needs Plan; Benchmark Plans
  - LTC partnerships;
  - Family Opportunity Act;
  - MFP demos;



# *Benchmark Benefit Packages*

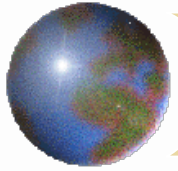
Four states are using this option

Two major ones:

- Kentucky
- Idaho's

Two others:

- Virginia's Healthy Returns Disease Management Programs
- Washington's Disease Management and Care Coordination Plan

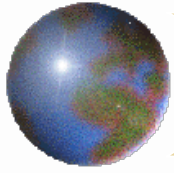


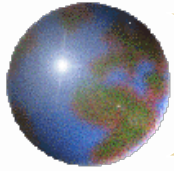
## ☉ Benefits

- ☐ Efficiencies
- ☐ Smooth transitions from one time of life to another
- ☐ Shared learning

## ☉ Concerns

- ☐ Loosing our Core Values
- ☐ Loss of constituency culture?
- ☐ The most severely disabled can be left out





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