



# Residential Services in the U.S.

---

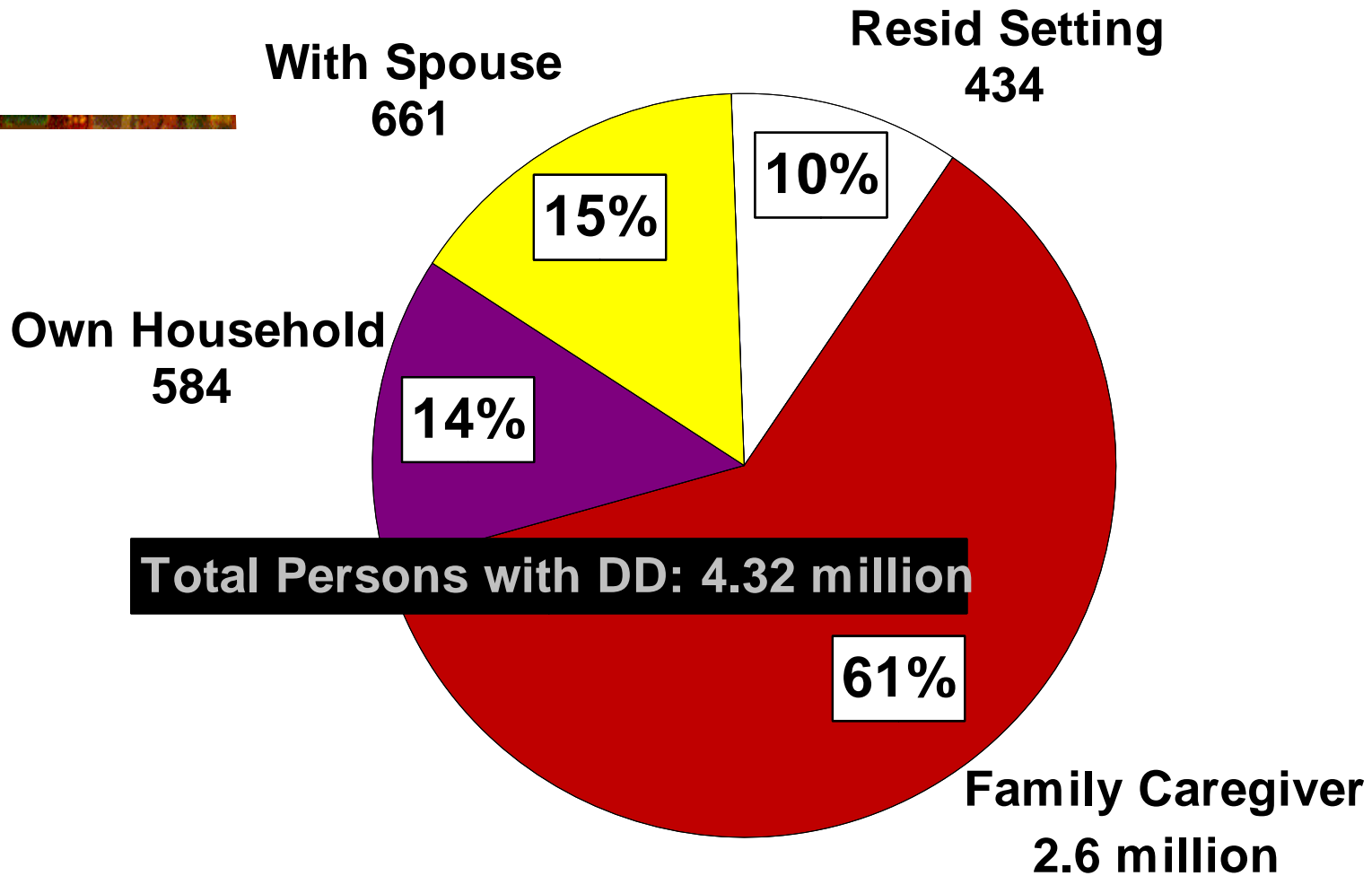
Susan L. Parish, Ph.D.

Presented at the:

International Rett Syndrome Association Meeting

Chicago, 2002

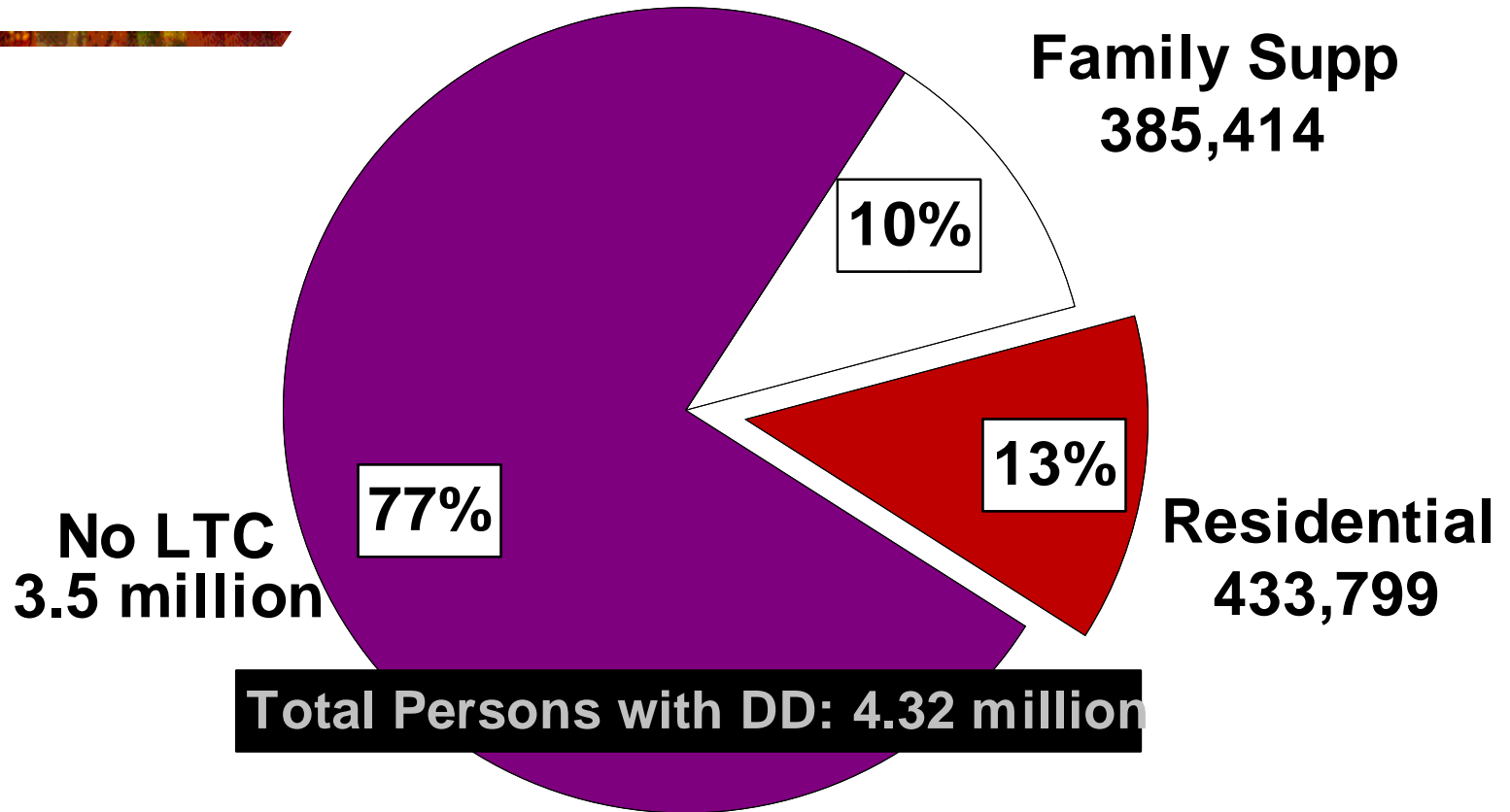
# Americans with DD by Living Arrangement (thousands): 2000



# Overview of U.S. Residential Services

- No federal law (unlike education) mandates residential services – there is no entitlement
- States (sometimes local government) generally license & fund services
- Administration is usually coordinated through states' MR/DD agencies
- Medicaid is largest source of funding for residential services in U.S.
- Ongoing trend: Downsizing of large facilities; Expansion of individual-scale services
- Enormous unmet needs (>87,000 in 1998)

# Americans with DD by Support Received: 2000



# Critical Issues

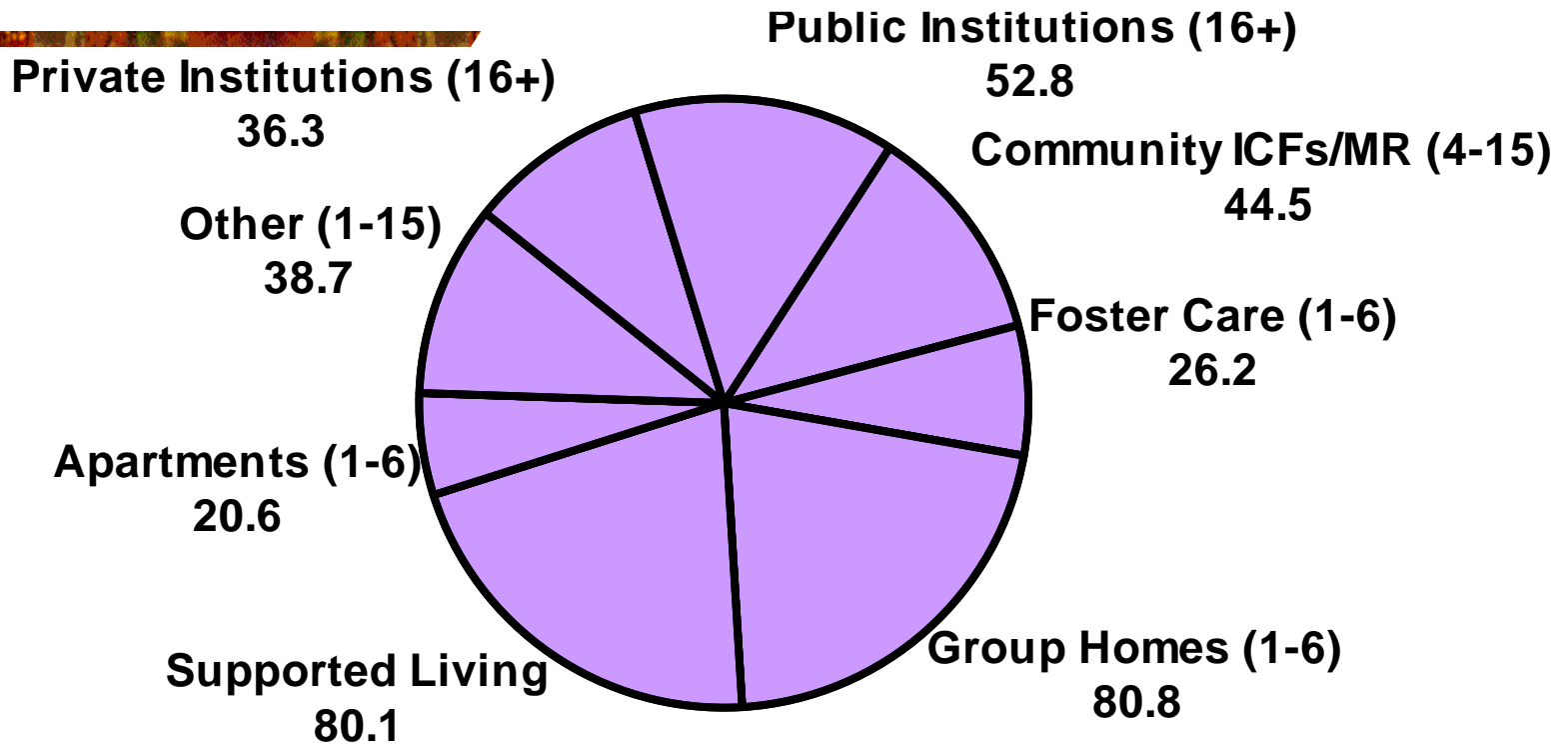
---

- Housing type
  - Home ownership
  - Financing strategies
  - Support services & management
  - Quality assurance
  - Waiting lists
-

# Housing & Home Ownership

- Separation of housing from services
- Housing types: group homes, apartments, supported living, foster care
- Except for foster care, housing type does not have to dictate services
- Common Funding Sources: ICF/MR, SSI, HUD, low-income tax credits, parent donations, other donated housing stock
- Home ownership: service recipients, parents, non-profits, for-profits investors, etc.

# Residential Recipients with DD, by Setting Type (thousands): 1998



**Total Residential Recipients: 417,819**

# Financing: Medicaid & Social Security

- States receive federal reimbursement 50-80% of expenditures, depending on state wealth
- 2 central programs: ICF/MR & HCBS Waiver
- Reimbursable programs vary by state, include residential, day programs, case management, etc.
- Pro: Allows state to leverage own resources & obtain federal funds
- Con: Federal regulations often perceived as burdensome
- Social Security: SSI, DI



# Financing: ICFs/MR

- Optional Medicaid service (all states participate to some extent)
- Characterized by regulations & medical services
- “Active Treatment” requirements
- \$3.2 billion spent in 2000 for public & private institutions
- \$1.1 billion spent in 2000 for facilities serving 4-15 people
- Not considered best practice – services are not individualized; high regulatory demands

# Financing: HCBS Waiver

---

- Part of Medicaid; federal reimbursement for allowable services (everything except room/board)
  - Allows states, with federal approval, to “waive” certain Medicaid requirements, (statewideness and choice of provider)
  - \$4.1 billion spent in 2000 on Waiver services for people with DD
-

# Benefits of the HCBS Waiver

---

- Flexibility: states can pick & choose service elements
  - Individualization of services is mandated
  - Leverage state resources to obtain federal reimbursement
  - States with strong Waiver programs have the greatest financial commitment for community-based services
-

# Support Services

---

- Staff supports can be continuous or intermittent
  - Supports can be individually tailored, or program-driven
  - Service providers can be religious or secular non-profits, for-profit corporations, parent groups
  - Best practice: separation of housing control from support service delivery
  - Financing: SSI, HCBS Waiver, ICF/MR
-

# Quality Assurance

---

- Best practices combine monitoring shared by parents, service providers, state authorities
  - Best practices monitor quality of services received, don't just prevent abuse or neglect
  - Different structures exist; sometimes state laws
  - Meaningful sanctions are necessary
  - Abuses occur in community settings & institutions: ongoing, committed oversight is critical
-

# Unmet Needs & Waiting Lists

---

- U of Minn researchers estimated >87,000 people waiting for residential services in 1998 across U.S.
  - U.S. Residential service system supported 433,000 people in 2000
  - Between 1995-2000, community placements expanded by 12,000 people (3%) annually
  - Great state variability – some states don't keep waiting lists
  - Urgency of need; planning for future
-

# Unmet Needs & Waiting Lists II

---

- 17 class action lawsuits across country attempting to force states to expand
  - Watershed 1998 Florida decision: Medicaid law doesn't allow states to indefinitely wait list individuals for ICF/MR services
  - Illinois case dismissed (February 2002)
  - Settlements: FL, HI, WA, MA, VA, OR, WV
  - The true scope of need is unknown; many families aren't on waiting lists
  - Families are reluctant to plan
-

# Comparing the States (2000)

- Top 5, residential services: IA, ND, SD, MN, WI
- Bottom 5, residential services: TX, AZ, KY, GA, NV
- Top 5, overall DD spending: ND, RI, NY, ME, CT
- Bottom 5, overall spending: AL, GA, FL, HI, NV
- Top 5 expanding (#): NC, WA, GA, AL, MS
- Bottom 5 expanding (#): CA, ND, WY, HI, AR
- Top 5 expanding (\$): ID, TN, AK, AZ, UT
- Bottom 5 expanding (\$): SD, NH, WY, IN, HI



# How do I get services for my daughter in 5-10 years?

- Make your needs known to the “authorities”
- Join waiting lists if they exist in your state
- Network with other families to learn the service provider system
- Connect with family supports
- Learn about the types of services that would be best for your daughter
- Learn the language of the service system
- Lay a foundation for advocacy: network with your state representatives, state agency personnel, service providers, other families

# How do I get services for my daughter in 5 years?

- Pressure your state or local DD agency personnel for placement (letters, phone calls)
- Become a priority to your state representative
- Be a very squeaky wheel
- Actively monitor waiting list status
- Continue networking with service providers
- Have your daughter found Medicaid eligible
- File a lawsuit
- Join with other parents/professionals & devise your own program

# How do I construct a program?

---

- Team up with families of people with whom you'd like to see your daughter live
  - Consider partnering with a provider
  - Raise funds for housing & start-up costs
  - Present a complete package to your local representative & get endorsement
  - Sell endorsed package to state DD agency
-

# What to seek in a provider

---

- Meaningful parent advising and/or control of the agency
  - Demonstrated track record of quality (accreditation, etc.)
  - Policies that encourage family participation
  - Policies that encourage family leadership
  - Respectful of family knowledge
  - Resources to meet changing times
  - Experience serving people with medical challenges
-

# Advocacy Strategies/Venues

---

- Target separate strategies for different audiences: newspaper editorial staff, elected officials, state agency personnel
  - What can you offer these targets in return for what they deliver for you? (Legislative breakfasts, "Meet the candidate" party,
  - Focus on the costs of care – institutionalization is generally more expensive than community care
-

# A savvy and successful parent...

---

- Is not intimidated by state DD agency personnel
  - Believes that her daughter is just as deserving and entitled to services as current recipients
  - Knows that he is the expert in his daughter's care needs
  - Learns how "the system's" red tape can be cut
  - Learns to effectively work in the state's political culture
-