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HOUSE RESOLUTION

WHEREAS, Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full inclusion and participation in the economic, political, social, cultural, and educational mainstream of their chosen community and United States society; and

WHEREAS, People who experience developmental disabilities, and their families, ask quite little, given their challenges; one thing that is critical to them is the confidence that, when needed, they will have access to the supports and services that will ameliorate a crisis or trauma and that will provide long-term stability and quality of life for them; confidence at this level requires a long-term public policy that guarantees that needed opportunities for supports and services are available each year; it also requires the confidence that the supports and services that are available are responsive to the needs of the individual; and

WHEREAS, Individuals with developmental disabilities should be supported individually, and individual choices and preferences should be the primary source of direction for services and supports they receive; and

WHEREAS, Federal law and recent court cases have clearly defined the State's responsibility to support each person's choice to live in the community of his or her choice rather than in an institutional facility; and

WHEREAS, The United States Supreme Court decision in *Olmstead ex rel. Zimring v. L.C.*, 119 S.Ct. 2176 (1999), held that persons with disabilities have a right to receive

1 State-funded services and programs in the most inclusive
2 setting appropriate to meet their needs and to participate in
3 community life to the fullest extent possible; and

4 WHEREAS, The State of Illinois, through the Department of
5 Human Services, intends to incur capital and operational costs
6 to develop and operate 4 10-bed intermediate care facilities
7 for the developmentally disabled on the grounds of the former
8 Lincoln Developmental Center, which is physically segregated
9 from the surrounding, mainstream community; and

10 WHEREAS, This Department development project is being
11 designed and negotiated without any direct involvement of the
12 40 people who experience developmental disabilities who may be
13 asked to live in that institutional facility complex; and

14 WHEREAS, The development of living environments and
15 program components in such facilities without the direct
16 involvement of the people who experience developmental
17 disabilities is in direct conflict with long-standing and
18 well-articulated Department policy on person-centered planning
19 and very clear and well-articulated national standards of best
20 practice for the development of supports and services for
21 people who experience developmental disabilities; and

22 WHEREAS, The aforementioned Department project perpetuates
23 the current supply-driven approach to services, which is not
24 based on what people who experience developmental disabilities
25 articulate as their need but which in actuality seeks to
26 redress the needs of other, non-disabled people or communities;
27 and

28 WHEREAS, The aforementioned Department project perpetuates
29 the over-reliance on State-operated developmental centers to
30 provide economic development rather than serve individuals
31 with developmental needs; and

1 WHEREAS, The Illinois developmental disabilities system
2 has been demonstrated to have institutional and congregate
3 capacities that are significantly above the national norm and
4 inconsistent with consumer demand, which forces those same
5 individuals with developmental disabilities and their families
6 to choose services they don't need or don't want or to not be
7 able to access services at all; and

8 WHEREAS, Recent national experience demonstrates that
9 economies of scale assumed to be associated with large
10 institutional facilities do not exist or are not equal to
11 related reductions in costs that are offered by supporting the
12 choice of people who experience developmental disabilities to
13 access appropriate community care; and

14 WHEREAS, The supporting access to appropriate supports and
15 services in the community, developed and designed in response
16 to consumer choice, represents sound public policy because it
17 is the right thing to do for citizens who experience
18 developmental disabilities and are vulnerable and
19 disadvantaged and experience difficulties and because the
20 direct and indirect benefits to the community as a whole are
21 both positive and tangible; and

22 WHEREAS, The aforementioned consumer-driven approach would
23 be more effective and efficient and would support existing,
24 sound public policy and a cohesive policy and planning
25 structure; and

26 WHEREAS, Our nation and the State of Illinois must offer
27 the opportunity for and support all people who experience
28 developmental disabilities to realize their own vision for
29 their lives; to accomplish this, families, friends, allies,
30 communities, provider agencies, professionals, advocates, and
31 government alike must work in partnership to do whatever it

1 takes to enable each individual to realize her or his unique
2 vision, and this will happen only when public policy decisions
3 are organized first and foremost around the choice and needs of
4 individual citizens who experience developmental disabilities;
5 and

6 WHEREAS, The State has a fundamental responsibility to
7 allow people with developmental disabilities now residing in
8 communities and State-operated facilities to determine where
9 they want to live based upon sound principles of
10 person-centered planning; therefore, be it

11 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE
12 NINETY-THIRD GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that we
13 strongly urge the Governor, the executive and legislative
14 branches of State government, and the Illinois Department of
15 Human Services to do the following:

16 (1) Take the immediate actions necessary to redirect
17 and utilize existing appropriations in the capital and
18 operating budgets and the proposed FY 05 executive budgets
19 of the Capital Development Board and the Illinois
20 Department of Human Services that are earmarked for the
21 Lincoln Developmental Center to support 40 individuals
22 with developmental disabilities;

23 (2) Develop a model approach consistent with national
24 best practice for person-centered and consumer-directed
25 planning and service delivery to identify and develop the
26 living environments, supports, and services for the 40
27 identified individuals;

28 (3) Consult with a nationally recognized expert in the
29 field of developmental disabilities, person-centered and
30 consumer-directed service planning and service delivery,
31 and the community-based systems of services to assist the
32 State in formulating the model approach and to oversee the
33 development of person-centered and consumer-directed
34 individualized support plans and appropriate funding

1 allocations, using the following principles:

2 (a) People and families must participate as valued
3 and empowered partners in all decision-making;
4 opinions of individuals and families are continuously
5 sought to inform policy making and system improvement;

6 (b) Family members, friends, and members of the
7 community can play an important role in enhancing the
8 lives of individuals with developmental disabilities,
9 especially when the family members, friends, and
10 community members are provided with the necessary
11 community services, individualized supports, and other
12 forms of assistance;

13 (c) Each person shall have the authority to define
14 and pursue his or her own vision; individuals with
15 developmental disabilities and family members feel
16 welcome to express their ideas, needs, and
17 preferences, as well as lead and direct the development
18 of their support plans with assistance, as needed, from
19 service coordinators, guardians, and other similar
20 persons;

21 (d) Self-determination or consumer-direction is
22 the organizing principle for service planning and
23 delivery; people and families are entitled to freedom,
24 authority, and support to control, direct, and manage
25 their own services, supports, and funding; individuals
26 have the capacity and the right to choose where and
27 with whom they live;

28 (e) Personal relationships and community
29 membership are valued; people have support to take part
30 in social, spiritual, recreational, and community
31 activities of their choice;

32 (f) All networks and systems of support must
33 collaborate in support of the person's vision; people
34 have one plan that pulls together all sources of paid,
35 generic, and natural supports in pursuit of their
36 personal vision; and

1 (g) There must be resolute, continuous commitment
2 to achieve excellence in all dimensions of supporting
3 individuals and families;

4 (4) Demonstrate to individuals with developmental
5 disabilities and their families that there is a commitment
6 to long-range public policy goals that do not have an
7 institutional bias, and that this commitment offers as a
8 goal appropriate, quality, cost-effective supports and
9 services in sufficient quality to meet their needs, is
10 based solely on the direct articulation of needs and choice
11 by consumers, and results in a demand-driven system of
12 services and supports;

13 (5) Demonstrate the State's commitment to make related
14 public policy decisions that are consistent with
15 long-range strategic goals for people who experience
16 developmental disabilities that are developed in
17 partnership with people with developmental disabilities;
18 and

19 (6) File a report consistent with this Resolution and
20 paragraphs (1) through (5) with the House of
21 Representatives on or before December 31, 2004; and be it
22 further

23 RESOLVED, That we urge the Department of Human Services and
24 the Administration to cooperate in taking the actions set forth
25 in this Resolution; and be it further

26 RESOLVED, That copies of this Resolution be sent to the
27 Office of the Governor, the Secretary of the Department of
28 Human Services, the Director of the Office of Management and
29 Budget, and the Secretary of the Senate.