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**Testimony for the Human Services Committee on March 8, 2007 regarding
Raised Bill 7279: An Act Concerning the Money Follows the Person Program**

My name is Paul Ford; I am employed by the CT Association of Centers for Independent Living as the Project Director for the Nursing Facility Transition Project. An outgrowth of a Federal Grant, the project has enabled 150 individuals to transition from nursing facilities to the community. In partnership with the project's steering committee and Connecticut's five (5) Centers for Independent Living, the project has removed barriers that prevent people from leaving nursing facilities when the care they provide is no longer needed. It has also demonstrated that there is a significant cost savings to the state and that with the right supports and services, individuals with disabilities and elders can return to the community. Money Follows the Person will take the work we have done, and significantly expand it, developing the supports and services needed for 700 individuals to return to the community. Under Money Follows the Person, Connecticut has the opportunity to rebalance its systems of long-term care and significantly increase and improve community based services for all citizens with these needs

Under the Nursing Facility Transition Project, the first barrier identified was housing. It is a threefold problem: affordability, accessibility and availability. Through the efforts of the Department of Social Services Housing Unit and The Department of Economic and Community Development rental subsidies and home modification funding, have largely removed the first two. In its Money Follows the Person proposal, Connecticut has made a significant commitment to continue and expand these. The proposal also calls for the addition of Housing Coordinators who will assist individuals leaving facilities to find housing as well as access rental and home modification supports. The availability of housing will need to be addressed. Efforts will be needed to stimulate the development of safe, affordable, accessible housing in various areas of the state, notably the northwest and eastern areas.

Long-term care is an important issue for everyone. With our population ageing and medical advances, the likelihood that we or someone we know will encounter a need for long-term care increases. The choice to receive this care in the community vs. an institution is something everyone would want. Connecticut has many excellent programs and waivers that provide community based supports and services as an alternative to institutional care, however, there are many in nursing and other facilities whose long term care supports needs are not met by today's programs and waivers. Money Follows the Person will give the state the opportunity and resources to close this gap. The attached paper, developed by the Nursing Facility Transition Project's Transition Implementation Workgroup, details the additional supports and services needed.

I encourage you to supports legislative and other efforts to implement Money Follows the Person. Thank you.

“My Community Choices”
Nursing Facility Transition Project

Transition Implementation Workgroup

Individuals with Cognitive Disabilities, and Others,
Whose Long-term Care Needs Include Assistance
with Management of Supports and/or Life Issues

Executive Summary

The Nursing Facility Transition Project, established by a Federal grant in 2001 and now continued with State of Connecticut Medicaid Funding, assist individuals in CT Nursing Facilities to return to the community. Individuals accepted into the project are Medicaid eligible residents of CT Nursing Facilities, seeking to return to CT communities, and who are identified by the facility as either long-term residents, or individuals at risk of becoming long-term residents.

Currently in Connecticut, many individuals enter a nursing facility for short-term care or rehabilitation. If the individual does not return to the community, within a period of time (generally three months), they become long-term residents. By this point their income is diverted to support them in the facility and they have lost their housing, possessions, and natural supports in the community. For most, returning to the community means starting over with nothing to build on. These are the majority of individuals seen and transitioned under the Nursing Facility Transition Project.

Connecticut has a good system of state programs and Medicaid Waivers to support individuals in the community. These include the Personal Care Assistance (PCA) Waiver, the Acquired Brain Injury (ABI) Waiver, the DMR Waiver, and the CT Home Care for Elders Program. These and other waivers and programs are all tied to specific disabilities, age groups or need for hands on assistance. They meet the needs of many individuals; however, for many others their needs are not covered or met incompletely. The result is ongoing risk of nursing facility placement, the inability to leave a nursing facility, or the reality of transition from a facility to the community and trying to manage, with only informal supports (family and friends).

Initial discussions within the project’s Transition Implementation Workgroup focused on individuals with needs not met by existing systems and a need for a new Medicaid Waiver to meet these needs. We now believe the solution is a new system, which will support all individuals with long-term care needs in the community. This support system must focus on the individual’s functional need, rather than specific disability or diagnostic criteria and include assistance with management of supports and life issues.

“My Community Choices”
Nursing Facility Transition Project

Transition Implementation Workgroup

Individuals with Cognitive Disabilities, and Others,
Whose Long-term Care Needs Include Assistance
with Management of Supports and/or Life Issues

I. INTRODUCTION & BACKGROUND

In the past few years, we have begun to see a number of individuals in nursing facilities who could transition to and be supported in the community if the right array of supports and services were available. Initially, this group was largely comprised of individuals with advancing Multiple Sclerosis and other conditions where there was a cognitive component to their disability that prevented them from managing their supports and services independently. This initial group often had physical disabilities and could qualify for the Personal Care Assistance (PCA) Waiver if the management of supports were not an issue or if there was a conservator or other individual willing to assume primary responsibility in a person centered manner. The services available under the Acquired Brain Injury (ABI) Waiver would meet many of their needs; however they were ineligible either because their disability was not an acquired brain injury or because their disability was progressive or degenerative.

As our work progressed, the group of individuals whose needs could not be met grew to include individuals with disabilities who had little or no life experience, and/or disabilities (including individuals with multiple disabilities) where the nature of the condition affected their ability to manage their lives and supports. A significant sub-group is individuals with Spina Bifida with hydrocephalus. Again, the service menu of the ABI Waiver is a possible solution; however, these individuals are not eligible based on the diagnostic criteria for that waiver, as their condition was considered developmental.

As we explored the data, the case scenarios for all of these individuals and our learning from working with them, we began to develop a menu of services we believe must be included in a new waiver.

As our discussions have progressed, we have come to the conclusion that **the true need is for a service delivery system**, whether it be a waiver, state program, State Medicaid Plan Service or something new, evolving out of the new options available under the Budget Reduction Act for State Plan Services, **that meets an individual's functional needs**, whether management of supports is an issue or not. From this, we developed a list of services designed to meet the functional needs of any individual in need of long-term care services and supports. This is **not based on any specific disability, diagnosis or criteria**: simply the individual's functional needs.

Though many individuals may not be fully able to manage their supports, the process must always be person-centered, evolving from a team process when appropriate, led by a clinical specialist with expertise in the specific needs of the individual.

Our vision is a “money follows the person” or “cash and counseling” type of system, where individualized budgets allow for the selection of supports and services from a wide menu. The menu must, over time, be capable of being expanded as new needs emerge in people needing long-term supports. Quality Assurance must be an integral part of the process. The supports and services must be available to qualifying individuals across the life span and integrated with other state programs that promote independent living, self-sufficiency, employment, and consumer control. [An example from the current system is the Medicaid for the Employed Disabled (MED) Program.] Any cost caps for the services must be aggregated across all individuals served rather than individualized, to allow the maximum number of individuals to be served. Individuals with progressive conditions must not be excluded; rather the system must adjust to their changing needs.

One final note: Many of the individuals we have seen, especially those with Multiple Sclerosis, have significant work histories and therefore higher than average Social Security Disability Payments. In some cases, they also may have pension or private disability income. Income and asset caps for eligibility programs must not exclude individuals who have significant work histories and income. They may and should contribute to their cost of care, but must not be locked out of service options simply due to the fact that they have so-called “excess” income.

II. MENU OF SERVICES

The goal is to provide a menu of services which will allow consumers to receive those needed services to enable them to live in the community and which can change, as the individual’s needs change. Flexibility in the system must allow for purchase of any support or service needed to support the individual, including services and supports not specifically identified in the menu we propose. All supports, services and related costs will be delineated in a service plan developed by a team of individuals who are chosen by the consumer and who have the needed expertise and/or experience to assist in the development of such a plan. The team leader will be an individual with significant background in Independent Living Philosophy and where appropriate, necessary clinical credentials. Individuals providing services will also have significant background in Independent Living Philosophy and where appropriate, necessary clinical credentials as well as training relative to the consumer’s unique needs and disability(ies). Specific training and credentials of providers to be established by team.

Chore Services
Cognitive Behavioral Services
Companion/ Personal Care Assistant Services
Community Living Support Program
Community Transition Services
Consultative Services
Environmental Modifications & Specialized Medical Equipment
Family Support and Psychoeducation
Home Delivered Meals

Homemaker Services
Independent Living Skills Training
Mobile Crisis Assessment & Stabilization
Peer Support
Personal Care Assistant Services (PCA)
Personal Emergency Response System
Personal Management Services
Pre-Vocational Services
Respite
Transportation
Service Coordination/Care Management
Substance Abuse Treatment Services
Supported Employment
Support Services, Assistive Technology & Materials

IV. DESCRIPTION OF WAIVER/PROGRAM SERVICES

(Costs identified are given where known, based on existing or proposed programs)

Chore Services-Services designed to provide one time or seasonal assistance with larger tasks related to maintaining a home in the community. This may include, but are not limited to, snow removal, seasonal clean-up, painting or major cleaning. Services will be delineated in the consumer's care plan.

Cost: \$25.00/hour

Cognitive Behavioral Services- A combination of therapies designed to provide both insight and understanding into negative thought patterns related to emotional disturbances, and to assist the consumer to establish more productive ways of living.

Cost: Unknown

Companion/Personal Care Assistant Services-Services of a trained companion to assist with socialization, leisure and recreational pursuits. Companions may provide limited personal attendant care such as assistance with feeding.

Cost: \$14.08/hour

Community Living Support Program-Services and supports provided in a small group community residential setting with one or two other individuals. The arrangement provides a full range of services and may include 24 hour wrap-around supports through a combination of services.

Cost: Unknown

Community Transition Services-Time-limited services and supports provided prior to the discharge of a consumer from a hospital, nursing facility or ICF-MR that are designed to facilitate the discharge or to support continued community tenure for a consumer covered under the waiver/program. This will include transition services for up to six months following transition. More time can be approved by the Department of Social Services.

Cost: \$35.00/hour

Consultative Services-Services available to the planning team, community transition service providers, service coordination/care management providers, personal management service providers and or others identified by the planning team to facilitate their involvement in planning or service provision. These services may include clinical specialists.

Cost:

Environmental Modifications, Technology, & Specialized Medical Equipment-

This includes the following:

- 1) changes in physical plant or vehicle modifications designed to promote accessibility/use and
- 2) specialized medical equipment or supplies (includes devices, controls, or appliances), detailed in a plan of care that enable consumers to increase their abilities to perform activities of daily living or to move within, perceive, control or communicate with the environment in which they live.

Cost: Maximum of \$10,000.00 with prior authorization.

Family Support and Psychoeducation-includes supportive counseling for first-degree relatives, partners or significant others of consumers covered under the waiver/program and basic education regarding cognitive disabilities, behavioral health disorders, community support resources, self-care and coping mechanisms for family members and strategies for supporting consumers served in the community.

Cost: \$47.14/hour

Home Delivered Meals-Meals on Wheels Service

Cost: \$4.65 per day Single/\$8.50 per day - Double

Homemaker Services-Agency or privately-hired service to maintain a home, including but not limited to routine cleaning, laundry, meal preparation, etc.

Cost: \$15.44/hour

Independent Living Skills Training-Training to enable the consumer to complete independently (with or without accommodations) activities and instrumental activities of daily living, recreation and leisure pursuits and/or engaging in community living. This service may include training in utilization of transportation or paratransit systems.

Cost:

Mobile Crisis Assessment & Stabilization-Includes an immediate face-to-face appraisal by a physician, mental health professional, cognitive disabilities professional or mental health practitioner under clinical supervision of a mental health professional, following a determination that suggests the consumer may be experiencing a crisis. The crisis assessment evaluates any immediate needs for which emergency services are necessary and, as time permits, the consumer's life situation, cognitive disability,

functional deficits, sources of stress, mental health problems and symptoms, strengths, cultural considerations, support network, vulnerabilities and current functioning
Mobile Crisis Intervention and Stabilization includes the following.

- A) Face to face, short-term, intensive services provided in the consumer's home and in any other non-office based community settings during a crisis. Mobile Crisis Intervention and Stabilization is designed to help a consumer cope with immediate stressors, identify and utilize available resources and begin to return to his/her baseline level of functioning. Such services also provide information regarding ways to avoid future crises and about how to access community resources to support continued stability. Crisis intervention must be available 24 hours a day, 7 days a week.
- B) Follow-up telephone contact with consumer who has recently been in crisis to monitor his/her present adjustment and to provide additional supports, as may be needed, in order to solidify gains made during the stabilization process.

Cost: \$115.00/assessment

Cost: \$65.00/face to face Mobile Crisis Intervention & Stabilization

Cost: \$32.50/telephone follow up

Personal Care Assistant (PCA) Services-Includes support with day-to-day activities to enable consumers to become more independent in the home and community. These supports may include some or all of the following:

- 1) Assistance in performing activities of daily living, including eating, toileting, grooming, dressing, bathing, transferring, mobility and positioning.
- 2) Assistance with other daily activities such as meal planning and preparation, managing finances, shopping for essential items, performing essential household chores, communication by telephone and other media and getting around and participating in the community.
- 3) Assistance with disability related issues, behavioral health or physical health-related functions, including prompting to take medication or prompting to adhere to self-management of a health condition.
- 4) Redirection and intervention to avoid risky behaviors. This includes observation and monitoring.

Personal Care Assistance may be consumer-directed. Personal Care Assistance should allow workers Compensation Payments allowing the individual to have a single personal assistant work more than 25.75 hours per week.

Cost: \$24.54/hour

Peer Support-Includes face to face interactions that are designed to promote engagement of consumers in addressing problems resulting from a consumer's disability and promoting the consumer's strengths and abilities to improve socialization, recovery, self-advocacy, development of natural supports, and maintenance of community living skills. Peer Support may also include interactions designed to stabilize the consumer during a crisis. Peer Support is provided by a person with a similar disability under the supervision of an appropriate professional. Peer Support services are directed toward achievement of specific goals defined by the consumer in his/her individual service plan.

Cost: \$16.00/hour

Personal Emergency Response System-Devices and equipment including monitoring services which allow a consumer to independently access outside emergency assistance.

Cost:

Personal Management Services-Personal Management Services include the following:

- 1) Ancillary support directed by the consumer to facilitate their engagement in school or employment
- 2) Guidance and assistance in developing systems, (which the consumer will learn and for which the consumer will eventually assume responsibility for) the management of supports and life issues. These services may include:
 - a) assisting consumer to discover the root causes of problems they encounter and strategies to prevent reoccurrence.
 - b) development, facilitation and maintenance of a circle of support.

The specifics of this service will be delineated in the consumer's plan of care.

Individuals providing these services will have the requisite skills and experience to assist the consumer in accomplishing their goals (as identified in their care plan).

Cost: \$35.00/hour

Pre-Vocational-Services that prepare the individual for future participation in employment. These services will be primarily in the areas of achieving the required level of concentration, task orientation and development of communication and work skills appropriate for interaction with employers, supervisors and counselors.

Cost: \$35.25/hour

Respite-This includes both "in-home" and respite outside the home. In-home respite involves the provision of temporary services provided by a peer support counselor or an individual with appropriate training as identified in the consumer's plan of care in the consumer's home that are designed to defuse conflicts or resolve problems that destabilize the home environment. Respite outside the home involves temporary placement outside the home for the consumer or his/her roommate to defuse conflict or resolve problems for the consumer covered under the waiver/program. Respite may also be used as temporary lodging to facilitate transition to permanent housing or to provide short term relief to family or other informal caregivers. This may be to provide temporary relief during times when the caregiver is unavailable due to vacation or emergency as well as to prevent caregiver burnout.

Cost: \$23.72/hour In Home

\$24.80/hour Out of Home

Transportation-Enables consumers to gain access to waiver/program and other community services, activities and resources as specified by the plan of care. This service is offered in addition to medical transportation required under 42 CFR 431.53 and transportation services under the Connecticut State Plan as defined by 42 CFR 440.170(a) (if applicable) and shall not replace them. Transportation services under the

waiver shall be offered in accordance with the consumer's plan of care. Whenever possible, family, neighbors, friends or community agencies will be utilized to provide this service without charge. This service includes transportation which is accessible to meet the specific needs of the consumer.

Cost: Current IRS Reimbursement Rate (\$0.405 in 2005)

Service Coordination/Care Management-These services include the following:

- 1) Working with the consumer to develop and implement an individualized plan of care designed to ensure that the appropriate configuration of services is in place to meet his/her needs.
- 2) Promoting access to physical and behavioral health services.
- 3) Promoting continuity of care across service episodes and providers
- 4) Assessing the appropriateness of behavioral health care or physical health care used by the consumer.
- 5) Coordination of behavioral health and physical health services.
- 6) Providing assistance to clinicians and to the consumer to promote the optimal use of resources.

Care Management services also may include prior authorization of care, continued-stay, retrospective care reviews, discharge planning and provider monitoring to assure compliance with quality standards as well as other provider performance enhancement activities.

Cost: \$17.43/hour

Substance Abuse Programs-Individually designed interventions to reduce or eliminate the abuse of alcohol and/or drugs by the consumer that may interfere with the consumer's ability to remain in the community if not dealt with effectively. Substance abuse programs are provided in an outpatient congregate setting or in the consumer's community and include the following:

- 1) An in-depth assessment of the inter-relationship between the consumer's substance abuse and mental illness, cognitive deficits and/or other disabilities
- 2) A Learning & Behavioral Assessment
- 3) Development and Implementation of a structured treatment plan
- 4) On-going education and training of the consumer, his/her family members, caregivers and services providers around consumer-specific sequelae
- 5) Individualized relapse- prevention strategies
- 6) Periodic reassessment of the treatment plan and on-going support

The treatment plan may include both group and individual interventions and reflects the use of curriculum and materials adapted from a traditional substance abuse program to meet the unique functional needs of the consumers served by this waiver/program .

Linkages to existing community-based self-help or support groups such as AA, NA as well as faith-based groups may be a part of the treatment program. Providers of the treatment plan will communicate treatment regimens with all of the consumer's service providers. All Substance Abuse Programs must be documented in the plan of care and provided by individuals or agencies approved as providers of this waiver/program service.

Cost: \$42.45/hour

Supported Employment-services that allow an individual to participate in employment. Services are provided at the worksite and must be focused on assisting the individual to manage their disability(ies) and functional deficits. This is not intended for the learning of job tasks.

Cost: \$53.19/hour

Support Services: Assistive Technology & Materials-These services are contracted to individuals or organizations which meet an individual's unique on-going needs and may include, but are not limited to, bill payment services, financial management services, fiscal intermediary services, the purchase of materials consistent with the plan of care to meet the goal of community living and/or in-home child care. Support services may also include scribe/reader services and interpreters (Foreign or American Sign Language). Support services, technology and materials will be delineated the consumer's plan of care.

Cost: Negotiated up to \$50.00/hour

(Consistent with local going rates for comparable services)

Appendices

- 1) NFTP Transition Implementation Workgroup – Purpose, History & Membership
- 2) Nursing Facility Transition Project Data Abstract
- 3) Reference Listing of Related Documents

Appendix 1
“My Community Choices”
Nursing Facility Transition Project

Transition Implementation Workgroup

Purpose: To support and oversee the work of transition occurring under the Nursing Facility Transition Project.

Activities: This workgroup meets monthly. The meetings are strategically aligned with the regular meeting bi-monthly meetings of the Transition Coordinators. They are actively involved in this workgroup. The workgroup identifies problems and barriers in transition and seeks to generate solutions. Workgroup also helps process and identify solutions around specific individuals currently in the transition system.

History:

In 2003, the NFT Project first began to identify the unique needs and challenges faced by individuals with psychiatric disabilities. The workgroup convened a series of meetings of Mental Health Advocates. The outcome of these meetings was an increased focus on and identification of supports to meet the needs of individuals with psychiatric disabilities.

In 2004 the problems some individuals face after transition lead to a realization of the reality of risks in transition. Acknowledging consumer’s right to take risks, and the project need to ensure that consumers basic safety needs were met, the workgroup developed a crisis plan for the project. This plan has been utilized a number of times since.

Beginning in 2006 and continuing into 2006, the workgroup began to recognize an emerging pattern of individuals seeking to transition whose needs are not met through existing service delivery systems. In response to this the workgroup has developed a “White Paper” identifying the problem and proposing the sorts of supports needed to meet the needs of these individuals.

Current Members:

- Michele Jordan, State Independent Living Counselor: DSS - Bureau of Rehabilitation Services
- Liz Gianni, Parent of an individual who transitioned under the Nursing Facility Transition Project
- Sherri Ostraut – CT Community Care, Inc.
- Jennifer Glick – Department of Mental Health and Addiction Services
- Robin Leger – UCONN
- Kim Massey – Ombudsman for Long-term Care
- Paul Ford – Nursing Facility Transition Project
- Michael Warburton, Transition Coordinator
- Rick Famiglietti, Transition Coordinator
- Claudia Keeley, Transition Coordinator
- Gene Mann, Transition Coordinator
- Victor Xavier, Transition Coordinator

Appendix 2
“My Community Choices”
Nursing Facility Transition Project
Abstract of Data
Individuals with Needs Not Met By Current Systems

Since the start of the Nursing Facility Transition Project in June of 2002, we have had contact with 311 individuals, who sought to transition from a Nursing Facility to the community. 127 (40.83%) have transitioned to the community.

Not everyone who seeks to transition completes the process. People withdraw for a variety of reasons. For some it is the absence of services to meet their needs, including the need for support in managing their services. We have identified a number of groups of individuals that may fall into this category. These include:

- individuals with Multiple Sclerosis, especially in the advanced stages where there is cognitive impairment,
- individuals with Spina Bifida, who of the have subtle cognitive limitations,
- individuals with Parkinson’s Disease
- individuals who have has strokes, but do not qualify for the Acquired Brain Injury Waiver
- individuals with multiple disabilities.

Note: For purposed of this paper, we have not included individuals with Psychiatric Disabilities, or Mental Retardation, though functionally, many of their needs are similar, there are systems working to support them in the community.

Below is a summary of data from the Nursing facility Transition Project on individuals who meet these criteria:

16 Had a primary diagnosis of MS and ranged in age from 51-68 (81% were under age 65)

12 – No secondary or tertiary diagnosis
4 had a secondary diagnosis (1 each: Mental Health, Diabetes, Visual, and Stroke/CVA)

8 Had Spina Bifida and ranged in age from 34 – 57

3 had no secondary or tertiary diagnosis
1 has a primary diagnosis of Cerebral Palsy, and also has low vision as a result of diabetes. Spina Bifida is the tertiary diagnosis for this individual.
1 is legally blind, had mental health issues (major depression) and renal failure.
1 has mental health issues.
1 has had cancer.

One more person with Spina Bifida was referred, but left the facility against medical advice before the work of transition began. This individual also had issues with alcohol addiction.

Others:

One individual age 54 had a condition known as CADACIL – this is genetic condition which causes multiple minor strokes, leaving the individual with compromised mobility and cognitive functioning. Literature describes the results as being similar to Multiple Sclerosis and Alzheimer's disease combined.

Three (3) individuals had Parkinson's disease. Their ages were: 46, 53, and 74. One had mental health issues; the other two had no secondary or tertiary diagnosis.

Of these 28 individuals,
2 died before returning to the community.
9 Transitioned to the community*.
6 are still working on transition.

Of the remaining individuals one transitioned on their own, due to problems with managing supports, they have returned to a nursing facility. The others withdrew and are still in nursing facilities.

At least ten more individuals with disabilities not included in the above groupings, withdrew from transition as their needs could not be met by existing systems and they needed support in managing their supports.

* Though these individuals did transition, they face significant challenges, especially in managing supports and life issues. Some have significant support from family or friends. For others they struggle to maintain themselves in the community.

In addition to the groups of individuals above, we believe there are other groups with similar needs, but for whom at this time we do not have hard data. These include:

- Individuals with AIDS Related Dementia
- Individuals with Alzheimer's disease, especially individuals diagnosed before age 65.
- Individuals with brain injuries, where the condition is considered progressive or degenerative.
- Individuals with conditions sometimes referred to as rare or orphan diseases due to the low occurrence within the general population. Example: CADACIL

Note: Though at this point in time, some of the individuals identified in this paper may need nursing facility or similar care, for many, with the right supports, they could enjoy many years in the community before needing nursing facility level of care. Philosophically, we believe that all individuals can and should be able to live in the community; it is just a matter of having the right supports. It is our hope that the system will continue to evolve and provide these supports.

Appendix 3

Related Documents and References

1. Americans with Disabilities Act – 1990
2. 1999 U.S. Supreme Court's Olmstead Decision
3. Choices are for Everyone – Connecticut's Olmstead Plan
4. CT Olmstead Coalition – Minority report
5. CT Long-term Care Plan
6. What Worked in Connecticut – Best Practice Report of the Connecticut Nursing Facility Transition Project
7. Connecticut Advisory Commission on Services and Supports for Persons with Developmental Disabilities who do not have Mental Retardation – July 2002