

# Redesigning day programmes

The onset of symptoms of dementia among individuals with ID is a particular challenge for day programmes. No area of ID services better exemplifies a traditional programmatic emphasis on being in the community, controlling one's life, building a network of relationships, holding a job or going to a programme outside the home, and having more independence this year than one did last year. There is also research being reported that as many as 66% of person with ID experiencing dementia symptoms are unlikely to be in a day programme (see, for example, McCarron 2002). If consistent across providers, this is of great concern: at the very time when programming support needs are greatest, the philosophy and practices of day programmes are at odds with dementia needs, and discharges from day programmes will mean that programming resources will be at their lowest.

Dementia is a degenerative progressive disease, where the person's needs should be expected to increase and skill levels to decline. This does not mean, however, that all skills and interests are lost immediately or that persons with dementia will not benefit from programming and other stimulation (McCallion 1999). Needs of individuals will also vary and the journey through the stages of dementia, while similar, has its own unique aspects, further compounding the difficulties in providing appropriate day programmes. There are a series of challenges that must be addressed if day programming is still to be an option as dementia progresses. These include:

- ◆ Knowing the mix of services needed by each person with dementia and how they will change over time.
- ◆ Determining the best location to offer services among existing day programme sites, areas in the residential unit, quiet areas and therapy rooms.
- ◆ Being clear about what we are trying to achieve with the services we provide.
- ◆ Developing services that are sustainable as dementia progresses and greater numbers of persons with ID served by the programme experience symptoms of dementia.
- ◆ Developing dementia-specific day programmes.
- ◆ No longer focusing upon teaching new skills, but instead working to maintain existing skills and to find adaptations that continue enjoyment of activities despite loss of skills.
- ◆ Developing memory-appropriate *versus* age-appropriate activities.
- ◆ Providing opportunities for engagement and enjoyment rather than requiring active involvement.
- ◆ Balancing the needs and desires of different clients.
- ◆ Knowing what staff are able to do and what is reasonable, given timeframes and other constraints.

The challenge now is to understand what will work and to redesign day programmes accordingly. Addressing this challenge will require administrative support of a change in programming philosophy, redesign of the physical layout of day programme sites, staff reorientation and training, and a new programming model.

## Administrative support

Interviews with day programme administrators at six sites in New York State found assumptions that the purpose of programming was to support production, productivity and the acquisition of new skills and beliefs and that staff were available to offer support, but were not trained or expected to be actively involved in personal care. They also reported

that they did not have the right staffing levels, type of staff (particularly to support health needs) or physical facilities to offer a safe and supportive environment for individuals with dementia. They were not convinced that funders and regulators understood the issues, would provide the resources needed or would support continued participation in day programmes by persons with dementia. Similar concerns were raised by staff at the day programmes, even by those interested in maintaining the day programme attendance of persons with dementia. However, there was a willingness to explore alternatives.

Key interventions were to develop an understanding of the importance of skill maintenance and continued community participation, to identify training needs and offer training in dementia issues for administrators and staff, to expand relationships with health service providers in the community to further support continued programme attendance, to undertake low-cost environmental modifications that promoted safety and supported small rather than large group programming, and to work with dementia service providers in the community on the dementia-oriented redesign of day-to-day programming. The most critical outcome was changes in both written policies and in the day-to-day programme philosophy to support continued participation in day programming by persons with ID and dementia.

## Meeting environmental needs

Work with the six-day programmrs in two areas of New York State, supported by a grant from the US Administration on Aging, found that key areas for environmental modification were:

- ◆ Providing small group and one-on-one spaces, often by putting up dividers and walls and dropped ceilings where there were previously workshop-like areas and other large open spaces.
- ◆ Addressing dementia-appropriate lighting (reducing shadows), noise abatement, flooring (reducing glare/avoiding patterns) and way-finding cues.
- ◆ Creating a more accessible site with adaptive toilets and an adequate bathroom area (to enable staff to cope with toileting accidents rather than requiring discharge of persons with continence issues).
- ◆ Offering space to wander safely inside and out of the day programme, including sitting areas.
- ◆ Redesigning programme areas to provide some combination of gardens/kitchen/snoezelen area/memory room/pottery kiln/beauty salon.

These changes were found to create a safe place, but not at the expense of supporting continued independence. With donated materials, re-allocations of resources and staff effort average additional cost of renovations was \$7,000.

## Staff re-orientation and training

Key training issues in the six sites were improving staff understanding of the implications and progression of dementia, including strategies for identifying and supporting the person's remaining strengths; training in dementia-based activity delivery; re-orienting staff to find ways to support and maintain individuals, rather than focus on the documenting of reasons for discharge; developing menus of services and activities to be offered, rather than delivering largely the same programme to everyone; and team approaches to personal care and health and safety concerns. ►

### A New Programming Model

Drawing upon the literature on successful programming approaches for persons with dementia and an understanding of the impact on individuals of the progression of dementia (McCallion 1999), a programming approach was developed and implemented in the six sites that was:

- ◆ Multisensory in approach—offering activities and opportunities that may be at times stimulating and at other times calming,
- ◆ Supportive of existing skills and memories rather than teaching new things,
- ◆ Tailored to the likes/dislikes and previous experiences of the clients,
- ◆ Based upon offering activities rather than training and that utilised reminiscence, trips in the community, walks, simple exercise, massage, snoezelen, horticulture, pottery, art, music, aromatherapy, hair/make-up/personal grooming, and quiet times and spaces
- ◆ Underpinned by training in dementia issues for staff.

### Findings and Conclusions

Administrators and staff in interviews across the 12-month period of the study consistently reported that the changes resulted in a more calm, comfortable, and relaxed care environment in which staff believed they were more effective, and clients were more engaged (McCallion and Nickle 2005). Indeed, discharges of persons with dementia from the day programmes were reduced during the study period. Of 19 clients identified at risk of discharge at the beginning of the project, only four moved during the 12 months and these discharges were attributable to residential movement—either out of the catchment area of the day programming or to a residential setting where day programming was included onsite. The success in programme maintenance was largely attributed to the impact of the environmental modifications, the reorganised staffing, and the extensive dementia training staff received. Administrators also perceived that there was enhanced agency awareness and professionalism regarding ID, aging, and dementia (McCallion and Nickle 2005).

The findings here may be a model for other day programme providers and more detailed information on the environmental modifications, staff training and programming redesign are available (McCallion and Nickle 2005).

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## Environmental modification

There has been increasing interest in the impact of physical environments on continued quality of life for persons with intellectual disabilities as they experience symptoms of dementia. There is both work with the generic population with dementia to draw upon (see references), targeted work with persons with ID and on-going work in Ireland involving multiple services providers and in the US with a consortium of agencies in New York State that are the basis for a range of recommendations for the remediation of key environmental concerns and to support aging in place.

### Aging in place

When symptoms of dementia are present, living in the community simply for the sake of living there, regardless of the quality of life that is possible, may be as indefensible as automatic movement into more restrictive settings. It is incumbent upon service providers to examine their settings and to work with families in looking at their homes to find relatively low-cost improvements that sustain aging in place and quality of life for the person with dementia. For most individuals, this affects the design of house in which they live as it reduces the home-like quality, character and appearance of the home itself. Chafetz (1991) suggests that there are seven dementia-related areas that need to be addressed: (1) simplification of the environment, (2) way finding and orientation (3) furniture (4) noise (5) illumination (6) colour, and (7) flooring. In a project working with 10 providers and 6 family homes in New York State (McCallion and Nickle 2005), we added (8) bathroom management, (9) kitchen safety and (10) supports for wandering.

#### *Simplification of the environment*

Key activities were the elimination of clutter, trip hazards, confusing layouts and other barriers to independence, and offering assistance where there were risks for confusion, or falls. Specific helpful modifications included:

- ◆ Installing double railings on stairs
- ◆ Installing hand grips at the top of a step or stairway
- ◆ Calling attention to steps with contrasting colours or reflective tape
- ◆ Reducing the height of a step by adding a mini-ramp or second step
- ◆ Replacing steps with ramps
- ◆ Replacing raised doorsills with flat plates.

In several cases masking the doors (using door posters and strategically placed large plants) of areas families or staff did not want the individual entering also contributed to environmental simplification.

#### *Way finding and orientation*

A three-step process was found effective in guiding these efforts (McCallion and Janicki 2002):

- ◆ Environmental scanning: examining the home for environmental barriers to aging in place, wayfinding and quality of life.
- ◆ Environmental labeling: giving clues and prompts to support continued independent navigation of the home. This included painting important doors different colours and putting signs on doors, in hallways and on key appliances such as the refrigerator and TV.
- ◆ Environmental flooding: Finding multiple ways to support continued independence, e.g., not only labeling the door to the kitchen, but leaving that door open to give as many senses as possible (hearing and smell as well as sight) clues as to where it was located so that the person with dementia would find it on their own.

# and dementia: key recommendations

## Furniture

Selection of furniture that is sturdy, simple and versatile is particularly recommended (Brawley 1997). Particular recommendations include:

- ◆ Light-weight items such as lamps secured or removed
- ◆ Table tops/cloths smooth and pattern free
- ◆ Furniture such as tables with rounded edges that are not sharp
- ◆ A variety of seating choices in day rooms and dining rooms
- ◆ Large dining room tables replaced with small ones seating 3-4 people
- ◆ Seating areas provided in long corridors.

## Noise

Hard, smooth surfaces and materials reflect rather than absorb sound waves. The acoustics of environments can be improved by installing carpeting, acoustic tile, ceiling baffles, heavy wall hangings, curtains and other sound-absorbing materials (Brawley 1997). Particular attention was paid to the acoustics of dining rooms and day rooms, the reduction of background noise from TV and radio/stereo and to helping staff/families understand the impact of their own social interaction to noise levels.

## Illumination

Shadows are a common source of visual illusions in persons with dementia (Brawley 1997). Efforts therefore targeted dispersing direct sunlight with curtains or tinted glass, avoiding glare by using indirect lighting controlled with dimmer switches and addressing sudden changes in light levels between and within rooms. In several homes, flooring was found to add to the problems: reflective surfaces such as shiny, waxed floor tiles contributed to light problems and were replaced. A particular problem for some is that mirrors often cause confusion; the person may not recognise their own image. This was assessed individual by individual and in two cases the mirror was removed from a bedroom.

## Colour

Colours in the red to yellow range are more accurately perceived by persons with dementia than blues and greens; solid colours or simple patterns are better than complicated or highly unusual designs (Brawley 1997; Calkins 1988). The opportunity was recognised to use colour in furnishings, floors and walls to assist in creating visual contrast. Pale colours blend easily with other pale colours, so instead in several cases service providers and families chose colours that were attractive and homelike, but which also offered contrasts: e.g., the presence of a handrail on a wall was better communicated by utilising a contrast colour. Similarly, in several homes a white light switch was contrasted with a dark switch plate, a toilet seat of a different colour contrasted a white toilet and a dark place mat under a light dinner plate offered additional visual clues.

## Flooring

Flooring presented the greatest concerns in family homes. Here there were more likely to be throw rugs in hallways, and patterned tiles in kitchens. However, group homes were more likely to have highly polished floors which presented their own concerns. In several cases flooring was replaced with simpler surfaces.

## Bathroom management

Two issues were of concern in bathrooms, the availability of adaptive supports and measures for water safety/control. Again there were differences between group homes and family homes. Group homes were more likely to have walk-in showers, so a primary intervention in family homes was the installation of grab bars, and hand-held, adjustable-height shower hoses and nozzles; training was also offered on the appropriate use of shower chairs. For group home staff training in shower chair use was also beneficial. Management of water was important in both settings because of fear of water damage and of individuals harming

themselves with overly warm water. The temperature of water was reduced in several cases, automatic temperature mixers and shut-off mechanisms were installed in others.

## Kitchen safety

Critical issues in kitchens were to find ways to improve access in areas that encourage independence as long as it remained safe, and to limit access when abilities and understanding had diminished to the point that supervision was necessary (Hutchings *et al* 2000). The desire of many clients to continue to access kitchen areas was recognised, so that the complete limiting of access to the kitchen was discouraged. Instead, cleaning supplies were relocated or placed in a designated locked cabinet; shut-off valves for water and the stove/cooker were installed, the arc of the kitchen tap was limited to the area over the sink and protective covers were placed on electrical outlets. In contrast, access was improved by labeling cabinets, leaving key utensils, ingredients and dishes on countertops so they could be more easily located and making sinks and countertops more wheelchair accessible.

## Support for wandering

Given weather conditions in New York State (hot summers and cold snowy winters), attention was paid to creating safe indoor and outdoor wandering opportunities. Gated and fenced garden areas were created, paths more clearly marked and pleasant areas created in gardens and on porches that encouraged the individual to sit quietly, as well as to wander freely and safely outside. Within the living unit, indoor walking paths were created that were free of clutter and offered opportunities to sit if the person became tired. There was also attention to safety issues. Silent alarms were installed on outer doors to alert staff or families that a person was leaving the building or an area where they knew the person was safe.

## Conclusion

New construction will necessarily be expensive and the resources are increasingly difficult to locate. Also the numbers of persons with ID and dementia are growing at such a rate that the most effective approach to living situations will be the support of ageing in place. There will always be a need for at least some specialised units, but attention to low-cost environmental modifications in support of safety, maintenance of independence and quality of life will be the best strategy for the majority of providers and family carers.

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