## REPORT on OPINION SURVEY conducted at ORANJ Plenary Meeting October 21, 2015

A questionnaire concerning issues arising from the mixing of IL/AL populations following passage of Americans with Disabilities Act and other legislation was distributed to those who attended the ORANJ Plenary Meeting October 21, 2015. What follows below is a summary of the responses received by the Health Care Committee.

The distributed survey and the survey data are attached to this report.

**Comments of Responders**

When asked if they expected to transfer to an AL facility as their health deteriorated or stay in their apartments, a large majority said they expected to transfer. Many people also noted in response to this and the next five questions some version of "it depends." Factors cited were:

- long term insurance;
- availability of spouse to care for one;
- degree of physical and mental limitations; cost of aides;
- whether a person could continue to have a reasonable social life, and
- whether the person's limitation would affect the daily lives of other residents.

A large majority of respondents felt that the resident mix had changed significantly with a major increase in the number of people who are older, more physically and mentally limited, more likely to use mobility devices, and more likely to have aides than in the past. Without a change in the law, people said, it is unlikely that these trends will change. So the question becomes how best to adapt. Many noted that CCRCs will need to hire more staff; specifically medical support services of various kinds, dining room staff, rehab. therapists, and housekeeping to care for the needs of the handicapped and their mobility devices.

Most respondents believed that residents should not be able to remain in their apartment regardless of limitations. Comments regarding limitations included: needing help with physical needs, need for wheelchair, need for an aide more than 2, 4, 8 hrs a day, confusion, dementia.

Overwhelmingly respondents felt that the CCRC should be able to require that residents with physical or mental limitations have specific services such as an aide, and the number of hours such services should be required. Some noted that these decisions should be made by the resident, his or her family, and the CCRC working together. As a part of this process, people said, CCRCs might be expected to evaluate all residents on a routine basis to identify changing needs and risks. Some respondents suggested that this evaluation and decision-making process should be spelled out in detail in the resident's contract.

Again overwhelmingly, the respondents felt that aging, the physical and mental limitations of the IL population and the increased use of mobility devices will significantly influence the future population of CCRCs. Most felt that CCRCs are becoming more like nursing homes and this makes it less likely that boomers or people in their 70s will apply. One person noted that

occupancy was already down at more than one CCRC, partly at least as a consequence of the changing population. Others noted that disabled people often are less able to participate in community activities. Some suggested that there be a 4th level between IL and AL for those with handicaps.

Cost was a factor discussed in that the addition of care services in the home is for the most part a cost to the resident. Movement to AL or LTC would also be a significant increase in cost to the resident. And the addition of medical, therapeutic, dining and housekeeping staff to the CCRC would affect the maintenance fees paid by all residents in IL.

Finally, the survey asked what changes people would like to see at their CCRCs. Here is a sampling of their comments:

- More availability of physicians, nursing staff.
- Longer hours for medical services, more specialized services (e.g. rehab) for aging population.
- More appropriate programs for the IL population that is truly independent, such as fitness programs, computer training, educational programs.
- Appropriate storage space for scooters, wheel chairs, walkers
- Required training for users of scooters and other mobility devices before they are able to operate them in common areas.
- Addition of a memory care center if none exists.

**Conclusions**

The addition in recent years, following national legislation, of people with various physical and even mental limitations to the IL population means that IL no longer means "independent" in the sense of being able to conduct one's daily life unassisted. Greater assistance for those in greater need will have to be provided and paid for by residents themselves. In addition, however, many residents would like to see their CCRCs also provide greater assistance in the form of increased staffing and programs tailored to the needs of this population. So far CCRC management has not made such adjustments and shows no interest in doing so. People would like to see systematic evaluation by CCRC staff of all residents to identify changing needs and risks which would combine medical expertise with resident and family wishes.

When the word "required" is used to refer to arrangements for the disabled population, we enter the realm of laws and legal regulation. On the matter of current law, not to mention possible future regulation that the senior population might want to see adopted, there is much vagueness and uncertainty. At present, the law seems to allow very little if any intervention in the wishes of disabled residents to live where and how they wish. In the absence of legislation on which to rely, the Health Care Committee recommends that ORANJ identify a list of "best practices" that would make the new reality safer and more comfortable for all.

**Recommendations of Respondents to Survey Questions**

**Mobility devices:** appropriate storage and user training

**Risk assessment:** systematic and on-going evaluation of needs and risks associated with residents' declining health and increasing infirmity. Even if the risk is not high enough to cause life-threatening harm, management should be aware as dangers arise and should discuss with residents steps to mitigate those dangers.

**Cost:** the added costs to residents of in-home health care, AL and LTC should be made clear in their contracts. The process by which these added costs are levied--who decides, how risk is assessed, how much and what kind of help must be paid for by the residents and how much will be borne by the CCRC – should be clearly stated in the contract. The contract should also state what consequences if any a resident would incur if he or she refused to pay for additional services.

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## Survey Distributed at the October 2015 Plenary Meeting

(This is Ron Whalen's cover tetter distributed at October 2015 Plenary)

### INDEPENDENT LIVING IN A CCRC

Now that CCRCs have been around for a number or years and many of us have resided in the Independent Living area of our CCRC for a number of years, there has been a change in the environment from what it was when we first arrived. The average age now is probably 80 to 85 years old, and the activity level of many of us has radically declined. And so, instead of an independent population, there now exists a population dependent upon aides, walkers and motorized mobility devices.

With the advent of and amendments to the Disabilities Act and the Fair Housing Act, since independent living units are considered your home, you cannot be required to leave them except for extraordinary circumstances. Based on the "Bill of Rights for Independent Living" which we have all recently received, one can occupy one's unit "as long as you can function independently, with or without the assistance of an aide or aides".
In light of all this, we have developed a survey to get your opinion on how you view this new environment, what you believe are positive and negative aspects, and what changes (if any) you would like to see.

It would be appreciated if you would complete this survey and return it to us today. Only if that is not possible, please complete and return it within the week to:

Ron Whalin, President, Fellowship Village
8000 Fellowship Rd. Basking Ridge, N.J. 07920

## SURVEY RE: INDEPENDENT LIVING

(note: Additional space left for responses has been removed from this facsimile.)

Name of CCRC_____ No. of Years of Residency: _____

1. When you first came to your CCRC, if your health failed, did you expect that:
___ you would be able to stay in Independent Living ___ you would transfer to
Assisted Living or Long Term Care ___Other _____

2. Do you feel that the resident mix in your independent living has changed significantly since you first came? ___Yes ___No. If yes, in what way

3. Do you feel that it is appropriate that you be able to remain in your apartment regardless of your physical or mental limitations: ___Yes ___No. If no, what would You consider acceptable limitations?

4. Do you feel that it is appropriate for individuals to be admitted to Independent Living with physical or mental limitations: ___Yes ___No. What would you consider acceptable limitations?

5. Assuming that people can remain in or be admitted to independent living with physical or mental limitations, do you feel your CCRC should be able to require that such residents have specific services (e.g. the services of an aide, the number of hours such services would be required): ___Yes ___No. If yes, please identify such services

6. Do you feel that the services available in your independent living accommodate the services needed by residents with limitations: ___Yes ___No. If no, please elaborate:

7. Do you feel that the aging and limitations of a large part of the Independent Living Population will significantly influence the future population of CCRCs. ___Yes ___No. If yes, how:

**8**. What changes/additions would you like to see in Independent Living for those with limitations as well as for those who are totally independent (e.g. changes/additions in Health Care, in Dining Services, in Rehab. Services, in utilization of space, etc.)

Additional Comments:

# Opinion Survey Data

## Approximate attendance at Plenary: 140

## Number of surveys returned to Health Care Committee: 67

**Number of responses from each CCRC**

| | |
|---|---|
| Applewood | 5 |
| Arbor Glen | 2 |
| Atrium | 3 |
| Bristol Glen | 0 |
| Cadbury | 1 |
| Cedar Crest | 7 |
| Crane's Mill | 7 |
| Crestwood | 3 |
| Evergreens | 2 |
| Fellowship V. | 9 |
| Franciscan O. | 6 |
| Fritz Reuter | 1 |
| Harrogate | 2 |
| Lions Gate | 0 |
| Meadow L. | 2 |
| Medford Leas | 3 |
| Monroe | 0 |
| Pines | 2 |
| Seabrook | 4 |
| Stonebridge | 3 |
| Wiley | 3 |
| Winchester | 0 |
| Total | 67 |

**Years respondents lived in in CCRC**

| | |
|---|---|
| 0 - 5 | 37 |
| 6 - 10 | 15 |
| 10+ | 13 |
| No ans. | 2 |

**Answers to Questions:**

| | | | | |
|---|---|---|---|---|
| 1 | Stay 15 | Transfer 42 | Other 10 | |
| 2 | Yes 52 | No 15 | | |
| 3 | Yes 22 | No 45 | | |
| 4 | Yes 29 | No 33 | Other 5 | |
| 5 | Yes 58 | No 7 | Other 2 | |
| 6 | Yes 50 | No 12 | Other 2 | no ans. 3 |
| 7 | Yes 59 | No 3 | Other 5 | |
| 8 | see summary of comments in report | | | |