



White Paper Addendum

by

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Introduction

Earlier this month, I sent out an initial White paper summarizing what I felt were essential issues facing the delivery of services to the Alzheimer's community. Seventeen people responded with written comments and several commented during informal conversations.

Results

Most of the comments were generally supportive of the arguments made in the paper. Typical of the comments were:

Professionals

- I think your paper is great. I agree with all of the points you have made. I have been saying for a long time that while we are doing a good job meeting the needs of people in the early stage of dementia, we are not doing nearly enough to meet the needs of those individuals whose dementia has progressed.
- You raise many important issues, which I would welcome the chance to discuss.
- Thank you so much for sending this! It definitely gave me food for thought and I really appreciate being able to read your thoughts on programming as a whole.
I'm very interested in creating programs that can be scaffolded so that folks at any stage are able to take part in activities and so that

there are entry points for everyone involved. It's so exciting to read your ideas on that in this paper and if you have any thoughts around ways you see folks doing that successfully, I'd love to hear them!

- I agree with you 100% with the fact that virtual and online programs are not as effective as meeting in person. These online programs were good for when we were on lockdowns and there were no other in person opportunities. They were a good alternative ONLY when we didn't have anything else available. When we are in the presence of other people, when we talk to people "In person", when we are able to see their eyes, their facial expressions, their body language we form deep connections that we cannot form when we only look at people's faces on Zoom behind a glass screen

Caregivers

- Wow. You summarized the issue perfectly! I agree with everything 100%. One thing to add, that these in-person events are also a huge resource for the caregivers. It gives the caregivers an opportunity to connect with others in the same situation and to share resources, which ultimately helps the person with ALZ.
- Ira's paper is necessary and invaluable as a starting point for discussion. Let's see what we can come up with to make our lives more enjoyable and meaningful.
- First of all, thank you for writing this paper. We can only hope that it kicks off some discussions and actions. I wish to commend you for addressing the issue of the need for more relevant programming directed to the Alzheimer's community. Through your White Paper, you have shone a well-developed light on the challenges, both for healthcare providers of services and to those of us for whom those programs are intended. I am in full accord that the successful delivery of services through programs must begin to rapidly transition to in-person delivery of services for the fullest possible benefits to our community.

Not everyone was as enthusiastic. Several people were concerned about those folks who do not live in Manhattan, cannot easily travel and are still concerned about Covid related issues. The following comments very clearly captured these concerns

- Thank you for your “two cents”. You raise an important issue namely, how do we provide services to people who are not as mobile or folks who do not live in Manhattan. Please stay in touch and any more ideas, please send them my way.

A second individual, who is a provider, while apparently comfortable with our basic argument went on to point out.

- We want to provide options of programming for folks not based in NYC or for folks who might find a barrier in not having someone to go to the program with or just not being able to leave their home on any given day.
- We are able to reach more folks by offering virtual opportunities as we do have a capacity limit for in-person programming.
- Many individuals have shared that if virtual programs were discontinued, they wouldn't have access to programming as they don't feel safe attending in-person programs right now. Covid for many is still an issue.

Suggestions

Several people suggested that virtual and in-person programs be conducted concurrently. That is an approach the Jewish Museum is already doing.

Note: Send us your comments and feedback and become a part of the change process by e-mailing me at ira@asherman.com