

## Study Guide

I have drawn up some questions which you may find interesting points of departure, or which might be used to start discussion after watching the film. Some of questions found below were concerns of mine as I made the film. Family, friends and professionals who work with people who have disabilities suggested others.

It goes without saying that these questions are offered as a starting point. You, no doubt, will have questions of your own.

Foremost, however, it is my sincerest hope my film has provided you with insights into the lives of people with disabilities and their families.

*Susan Hamovitch*

### General Questions

1. What is your overall response to the film?
2. Is there a particular scene that stands out in your memory?
3. Which person did you identify with the most?

### Secrets and Omissions

There are many moments in the film when the truth is withheld from one of the key players. For example, Susan isn't told that her brother is being placed in a facility. The day comes and goes and she still doesn't know where he's gone.

With this omission, the pattern has been set. The family has begun to "close down" to one another, and to the outside world on the subject of Alan. After Alan's placement, few friends — except the very closest — will know of Alan's existence.

Secrets of course occur for many reasons. And it is easy to blame the person who keeps the secret.

But put yourself in the shoes of Alan's parents. They've been encouraged by the then top doctors and psychologists to institutionalize Alan. They've held off on doing it for several years, however, trying various schools and programs. Finally, with no existing services in their community and running out of options, they do what they've been advised. Mitzi records the day in her journal. They dress Alan up "like a little prince -- short white pants and a plaid shirt" and leave "their beautiful son at Letchworth, in the Catskills -- forever"

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4. How do you imagine they felt on that day?
5. Was secrecy a kind of coping skill? In what way?
6. What effect does all this secrecy have on the person keeping the secret? Are there benefits?
7. And how would secrecy within the family affect the individual with disabilities?
8. While chronicling the experiences of a family of a previous generation, *Without Apology* has many parallels with things families are experiencing today. Siblings and parents talk today about how hard it is sometimes to talk to new friends, would-be boy and girl friends, classmates and colleagues about their family member who looks or acts differently. While the painful world of 50's shame and secrecy has, thankfully, been put to rest, there are still times when families may feel embarrassed, or like just not talking about their disabled family member.

Why *would* a sibling or parent feel more sensitive than a friend or staff member about a child's or sibling's "unusual" mannerisms or behaviors?

9. Why might they be reluctant to discuss their close relative altogether?

On the other hand, things *have* changed. Allow me to pose some ideas which can serve as follow up to Question #5.

The filmmaker's family experienced profound "embarrassment" about Alan – even shame. But with the transformations that have taken place in attitudes towards people with disabilities since Susan was a child, a young family today most likely would respond differently to the way the Hamovitch family did.

10. So, consider...how have the prevailing attitudes towards people with developmental disabilities changed over the last fifty years? What, if anything, has stayed the same? Are there any attitudes which are frowned upon today?
11. How might a young family with an "Alan" in their midst respond emotionally today?

### ***The Question of Placement***

12. One moment in the film which is often difficult for viewers is when Bill, the film maker's father, makes the claim that institutionalizing Alan was the right decision. He states that it was justified because, in part, he and his wife needed to provide a more "normal" environment for Susan, their typically developing child "Depending on how it affected you," he says, "it might have been better if it had been done earlier."

- a) How did this moment in the film make you feel?
- b) What do you think about the reason he gives? When one family member has serious disabilities, do you think the welfare of the other siblings should be an important consideration ?

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13. Institutionalization has been discussed at length in terms of how it impacted its residents. This film also looks at how it affected the people who remained outside its walls. Towards the end of the film, Bill Flynn remarks: “The family was told to put their child here and — forget about him” Thus there was little if any invitation for families to be involved with a brother, or son once he had been placed.

a) What was the film maker’s family’s reaction to Letchworth Village? Can you describe in a word the experience of visiting Alan there?

b) Did ‘Letchworth Village’ affect Mitzi differently to Bill, or Susan? How does each family member’s relationship to the institution differ?

### *Siblings*

*Without Apology* is often discussed in terms of its being a film made by a sibling. Siblings are increasingly acknowledged for the important roles they play in the lives of their brothers and sisters who have disabilities – from childhood often through old age. Siblings are also recognized as having needs and issues of their own, that are distinct from others in their families. Following are a few questions which get at the ‘sibling experience’ as portrayed by the film.

14. How does Susan feel towards her brother when they’re both young children at home? How do her feelings towards him change as they both age and their circumstances change?

15. When Susan tells her father that the visits to Letchworth make her sad, what do you think lies behind this feeling? Why do you think Susan stopped going with her family on their monthly visits?

16. Susan resumes her regular visits to Alan when she’s an adult in her 30’s. The precipitating event seems to be the sibling meeting she attends. Why would a meeting of this kind spur her to visit Alan?

17. How do her visits to her brother as an adult differ from the ones she took in the past with her parents?

### *Alan’s Placement in the group home*

18. When Alan moves into the group home, his mother is visibly changed. We hear Mitzi’s line from her journal: “I’ve come out of the closet. We can talk about Alan as an ordinary adjunct to the family.” Why does the move into the group home affect Mitzi so profoundly?

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### *Dreams*

During a typical visit after Alan's move -- as in the past, the format is a picnic in a secluded setting -- Mitzi can be heard speaking to Alan, breaking down the syllables of simple words like "da da" and banana. "Ba-" she says repeatedly, after giving him a piece of the fruit. Clearly her hopes have been raised by Alan's move into the normalized setting of a group home — to the extent that she thinks he might even speak, although he is now forty one years old!

Whether or not this dream of Mitzi's — that Alan would communicate with her — would ever be realized, parents and siblings both often hold deep-seated longings for certain kinds of abilities, or changes in behavior. In the filmmaker's family, once Alan was removed from the large scale institution, their dreams were rekindled and in their case, the primary one was that Alan would somehow convey his recognition of them, or that somehow, perhaps even by speaking, he would attempt a recognizable form of communication.

19. What are some of the hopes and dreams family members might have -- both realistic and not -- for their son, daughter, brother, sister with disabilities?
20. Can these family member visions, or hopes serve a purpose in the overall care and planning for services of a person with a developmental disability?

### *Alan*

These questions are drawn based on an exercise I conducted with the group that runs Alan's day habilitation program. I asked each person in the room to describe Alan in a single word, or phrase. I was surprised how widely the answers ranged, and how distinct my own "word" for Alan was from the others.

21. What word or phrase would you use to describe Alan?
22. If you were to spend an afternoon with Alan, would you take him hiking down the middle of a stream? What would *you* do together?
23. If you were given the chance to design Alan's daily life, in part or in its totality, what would you choose to change, or provide?

### *Systems*

24. How would Alan's programming be designed if he were a young boy of five years old today?
25. Alan's move into a group home is followed soon thereafter by a case review meeting. (Note that case review meetings had already begun while Alan was living in Letchworth Village.) During these meetings in the group home, Alan's father, Bill, was often quite assertive and at one point his temper flares. Feeling as though he was not getting a satisfactory answer to a question

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about the amount of recreational walking Alan was getting, he asks in a loud voice, "What difference does it make in his life!"

What do you think about Bill's temper flare-up during the meeting? Was it justified? How well did the team handle his questions -- and anger?

26. What difficulties are posed, if any, for family members by today's services and programs?

27. What changes should be made in the service system, which would further assist young families of today?