

## THE MAPS PLANNING PROCESS FOR OUR DAUGHTER ALEXIS

By Deb D'Luna

I first heard about the idea of futures planning while attending the CHARGE Syndrome conference in Costa Mesa, California in 2007. A couple of moms from California presented the technique of MAPs (i.e., Making Action Plans) and were very positive about the process.

As we approached Alexis's 22nd birthday, I became anxious about the end of my daughter's public education and the dramatic changes that would bring. My husband and I visited adult day programs of many different sorts: work, recreation, vocational, arts. We found it exciting and worrying. I developed charts to make sense of our options. The world of adult services is a big paradigm shift. I was prepared to *try* to think differently about my daughter – to focus on her abilities, achievements and potential for success.

At the same time, I realized that much of the recreational and social opportunities that Alexis enjoyed were evaporating along with her high school attendance. The natural proximity and energy of other young people with *and without* disabilities is something that Alexis takes for granted and thrives upon. I began fretting about how we could meet those needs.

Being in high school naturally makes you a part of a community. You are a high schooler and wear school spirit wear. There are cheerleaders, sports teams, a marching band, choral groups and clubs all identifying with, and proud to be, members of your high school. I wondered how we could replace or create a substitute for all that “community belonging” in Alexis's life.

I asked Gloria Rodriguez-Gil to facilitate a MAPs meeting. We determined that we would focus attention on the areas of social and community life. Gloria's suggestion that I preview the MAPs materials with Alexis was very helpful. I had intended to take it slow and perhaps go over a single category of the MAPs with Alexis each day (e.g., the likes and dislikes section). Gloria had provided me with a colorful, graphical representation of the process and Alexis related strongly to these materials. Each page had a person icon in the center and I wrote Alexis's name across the front of each icon. I told Alexis we were planning a meeting about her. Here is the link to the pages we used:

<http://www.nationaldb.org/documents/products/MAPSEnglish.pdf>

Alexis became so engaged that she wanted to keep on working through the different aspects of her life: likes, dislikes, strengths, dreams, and fears. We were very specific and Alexis really enjoyed the process. I think the process was a positive way to review her life and it helped her to think analytically about herself. Here are some examples of the information we generated with Alexis:

**Things she likes:** her family, parties, holiday decorations, chewing gum, movies & popcorn, having nails & hair done, travel – especially cruises, feeling proud, going out, being with people, a cup of tea

**Things she dislikes:** getting stuck or things getting stuck, being sick, being frustrated, people arguing, loud

voices, other people coughing or sneezing because of sudden loud noise, losing her balance, being alone outside in the dark

**Strengths:** working hard, concentrating, being funny, patient waiting, good swimmer, being a happy person, asking for help, delicate in movements, good manners, loving, keeps trying, good self-help skills.

**Dreams:** having friends to go out with, to go to college, work, be happy and healthy, live in apartment with friends.

My husband was somewhat doubtful about what the MAPs would accomplish. He felt that we were already well aware of Alexis's needs and singularly prepared to make decisions about her future. We were also both concerned that the process would put pressure on the attendees to do something for Alexis. We have always felt that planning and providing for Alexis is our responsibility and that others should not feel burdened or stressed by our situation.

Nonetheless, we set aside a Sunday afternoon and invited extended family, specific friends and care providers. I cast a wide net, but I was thoughtful about who I invited. My criteria for who to include was that the invitees should have demonstrated an interest in Alexis and be likely to be involved in her life in the future. There are many wonderful folks who could have contributed what they knew of Alexis and who care about her, but whose future involvement in her life is unlikely, so these individuals were not invited. Examples of attendees: her interveners, her final teacher, her yoga and piano teachers, and close friends who have a history of interacting with her and who are supportive of us as Alexis's parents.

I sent out invitations stating the date, time (including how long the meeting would last), location and that lunch would be served. Also, I included the following so that those invited would have some idea about the purpose of the occasion:

*Gloria Rodriguez-Gil of California Deaf-Blind Services will facilitate a futures planning meeting on behalf of Alexis. California Deaf-Blind Services is a federally funded project to support deaf-blind individuals in California from birth to age 22. Gloria Rodriguez-Gil is an educational specialist with extensive experience in the field of deaf-blindness.*

*You are among a small group of people who know, are interested in and care about Alexis. A happy, healthy and productive future is something that may not evolve naturally for Alexis and needs to be planned for. The purpose of this meeting is to develop a shared vision of Alexis's future. This vision will help us make choices that will bring about a truly favorable result.*

*We hope you can come because you have a unique perspective. Your participation will help us think about and plan for Alexis's future. You will not be asked to do anything except share what you know about Alexis, as well as your dreams for her future.*

Gloria was accompanied by two interns from the CDBS-San Francisco State University teacher training program in deaf-blindness. One intern wrote everyone's comments as bullet points on large pieces of poster paper which were taped around the room to be visible during the process. The other intern took notes on a laptop computer. This was tremendously helpful as Gloria was able to focus all of her attention on facilitating the meeting.

At the beginning of the meeting, Gloria provided guidelines to keep the meeting focused. Participants were asked to be concise and to direct their thoughts to the entire group. She also designated a timekeeper and kept us moving through each section so that we made swift and efficient progress. We did not break

for lunch, so everyone was invited to get up and serve themselves the sandwiches and finger food we had provided.

We are blessed with a supportive family who love and dote on Alexis. She is accepted and loved just as she is and everyone caters to her; telling humorous and amazing stories about her is a common family activity. Fortunately, everyone also always supports our decisions without question. The MAPs meeting was a real eye opener for our extended family because unlike us (with 22 years of IEPs behind us), they were unused to thinking analytically about Alexis. Seeing ways they could help her make forward progress was extremely empowering and everyone found a way they could contribute. Each of our family members has since taken the opportunity to express their appreciation for being included in the meeting, to say how interesting and helpful they felt it was.

For example, one of my nephews emailed us: “Thanks for sharing the MAPs. It’s been wonderful to be a small part of helping Alexis map out her near term future, and I look forward to helping her progress in the months ahead. I think, just like for all of us, if she takes on things in bite-sized chunks, that she’ll really flourish in the time ahead. I envision a wonderful future for her, where she continues to grow, and enrich the lives of all around her.”

My sister in law emailed: “Thanks so much for allowing us to have an active part in helping Alexis have such a productive life. You two have created this wonderful circle of friends, neighbors and family available to her by creating this immensely strong foundation for her to live her life as normal as she can. We feel she is so much a part of our own family and for that we have you all to thank for as we continue this journey with all of you. We will continue to do all that we have been doing and above as this new chapter in her life begins in 2010. We are available to you all anytime so please call. Thanks for including us in these life decisions as we love her so very much and very deeply and our love extends to all of you as well.”

Alexis’ teacher (a special educator of 35 years) wrote me a note of thanks that said the MAPs was the most productive and meaningful meeting she had ever attended for one of her students. “It was amazing!”

One of my friends was so impressed with the event that she told her daughters and husband about it in detail during the holidays when both girls were at home from college. Her youngest daughter, who is a junior at UCLA, approached her mom after hearing about the MAPs with a plea that the family do a MAPs on her in order to help her get through a stressful period when she couldn’t see the direction of her own future. As a consequence, my friend used Alexis’ results as the blueprint to do her own MAPs! The daughter even spent a couple of hours developing her own vision of herself (as Alexis had done). The young woman found this way of looking at her future potentials to be tremendously helpful; my friend said that she could see the anxiety lifting from her daughter as they progressed through the MAPs. She said it was a wonderful opportunity to positively point out not only her daughter’s tremendous gifts and potentials, but also areas of need. In that circumstance, the young woman was very open to hearing things that otherwise might have been seen as hurtful criticisms.

When I think back on the day we held the MAPs for Alexis, I feel pride about what we accomplished. My husband and I feel supported by the friends and family collected and focused on supporting us and can see the beginnings of a path of through the thicket of likely future difficulties and opportunities. The plan we developed that day has already been tremendously helpful in filling in the social and community gaps that quickly developed post-graduation.