



Person Centered Plan

Gannet Hosa-Betonte, 2014

A Special “Thank You” for 2014 PCP content:

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Introduction to Working With Gannet

A Personal Perspective

Working with and for Gannet as a coordinator/caregiver/facilitator has been and continues to be both challenging and very rewarding. As with any other human being, Gannet is a complex, intelligent, free thinking, at time stubborn yet flexible, and, above all, goes through the same emotions we all experience. In other words, Gannet is like anyone else.

In my experience, one of the biggest mistakes one can make while working with Gannet is to believe that he is a two dimensional being and worst off all “hard wired” with no room for change or improvement. Nothing could be further from the truth. In fact, over the years, Gannet has learned many new skills that he applies to his daily life and has shown great open mindedness and adaptability in new environment settings and activities.

The most challenging aspect of working with Gannet is and probably always will be how to give him the opportunity to lead his own life and, therefore, we, as caregivers/instructors, facilitate his own choices and decisions without doing it for him. This is difficult since Gannet might not always want to make the decisions and might not be forth coming in communicating with you. I truly believe that in order to be efficient when working with Gannet, one needs sometimes to step back and analyze what is being done and how it benefits Gannet.

Working with Gannet is personally very rewarding. Meeting goals and objectives, no matter how small or seemingly inconsequential, are in many ways great victories for Gannet and yourself that set the bar even higher for the next accomplishment.

Alex Gallego, Supported Living Coordinator and Roommate

What Is My PCP and Your Role?

Note: this Person Centered Plan is written in the first person from Gannet's point of view. While Gannet did not literally write this word for word, Gannet's direct communication input and life experiences are at the core of the content. The team feels that the first-person point of view helps Gannet to have a more compelling voice about personal preference in how he wants to live his life to the fullest to the best of his abilities.



Person Centered Means Gannet-Centric

The Person Centered Plan (PCP) enables my team (staff, friends and family) to better understand who I am and how I like to live my life. Understanding “who I am” enables staff to be more accurate and consistent when interpreting my intentions and needs, thus allowing me to control my life to the extent that I am able.

When new staff are hired, they need to read this document and understand that they are helping me live MY life, and that I have ideas and preferences. I do not want my life to be reinvented by a stranger, and I do not want anybody to impose their personal preferences or ideas on me, or mess with my lifestyle. This has happened to me in the past, and it's frightening for me to lose my identity and control. I never want that to happen again!

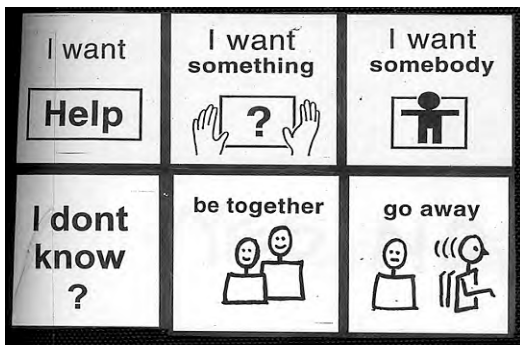
This Person Centered Plan is a living document, and can be amended as time goes by. This document is written from my perspective, and it also contains a collection of observations and notes by others in my circle of support, past and present. My “circle of support” has a responsibility to me, to share information and experiences with each other to keep my life consistent across all different aspects of my life, and to insure that this document keeps pace with my expanding interests and needs.

Additional personal guides on how to work with me, training videos with task-analysis, daily calendars and logs, reports, etc are on a server and available to people who work with me or who have permission for access.

I Have a Right to Make Decisions About My Life

I have a right to have control over my life, what I do, where I go, who I am with, and how I define my lifestyle and preferences. I also have say in making decisions about who lives and works with me. This might be a scary outcome, if I was completely left to my own devices. I need help from family and staff, who are well informed and respect who I am, to help me make the most appropriate choices and decisions that reflect my lifestyle and needs, and keep me safe.

My Conservator: I have agreed with the courts, and they have granted my mother, Amy Hosa, to be my conservator of person. If there is any question, she has the right to advocate and act on my behalf to intervene and determine appropriate choices and responsible decisions for me.

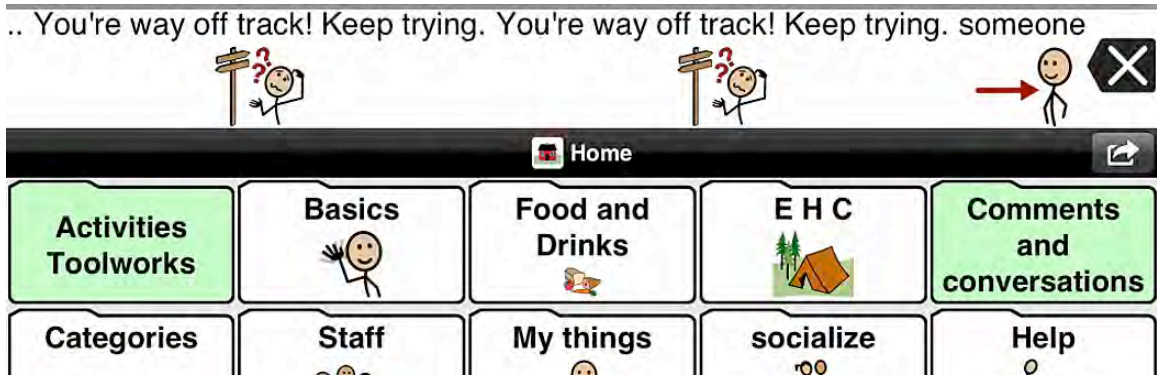


How Do You Help Me Make Choices and Decisions?

A Message from My Conservator of Person, Amy Hosa:

Right now, Gannet's decision-making behavior wavers between unpredictable, inconsistent, downright non-cooperative, or frightfully unsafe on one hand, to totally clear, direct, cooperative and taking action in his best self-interests, on the other.

When and how do we limit choices? When do we say "no" to his expressed choice? When does Gannet (or when do we) have to compromise? When do we have the responsibility to take over decision-making, and when are we trespassing on his rights? When is an option non-negotiable like "Yes, you need to go to work or class, unless there is due cause." When is a choice wide open? When is Gannet allowed to fail? There is no simple answer. We all need to weigh the consequences of each situation, **while we honor this Person Centered Plan document and follow through.**



Before saying “NO” a request or decision, try to get clear that you really understand what Gannet is trying to tell you. You might be “way off track.”

Decision Making Goals

I propose these 2 goals that we can work on together:

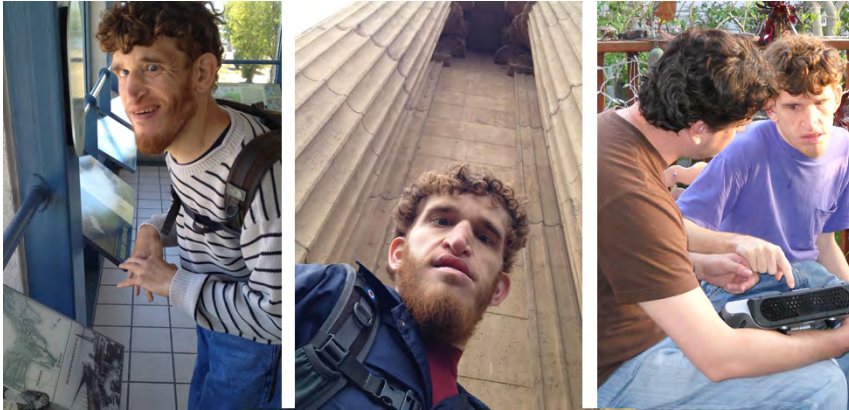
DECISION-MAKING GOAL for ME: I will be able to be more consistent, communicate with clarity, and act in my own best interest when making choices and decisions.

DECISION-MAKING GOAL for STAFF, FAMILY and FRIENDS: Your goal is to find ways to listen to and interpret my needs and desires, to explain various outcomes, and assist me in making “appropriate choices in my best interest” without stepping on my toes, or unduly influencing my decision or choice. Note: However, if you determine my choice is not in my best interest, or does not reflect my Person Centered Plan, or is unsafe, please say “no” and explain why I can’t do that, then ask me to consider alternatives.

I am a difficult person to understand. It takes time for BOTH of us to learn to talk to each other and trust that we really are communicating.

See the Task-Analysis Videos on Communication for training with samples of decision making conversations having various outcomes to get an idea of how to approach some confusing scenarios regarding making choices and logical or illogical outcomes.

Who is Gannet?



I Am an Intelligent and Capable Person.

I can also be inconsistent in my abilities because of neurological interference, so please be patient and understanding.

I appreciate having the opportunity to have choice in the decisions and outcomes of my daily life.

I need augmented communication systems to speak, and have always have things to say.

I understand conversations, and I have opinions to offer.

I understand what is read to me, whether it's a dinner menu or museum caption.

I have the ability to cooperate, and act socially responsible.

I like having books read to me. Books I've read are diverse, from Dylan Thomas' *My Life as a Dog*, to Tom Swift adventure stories, and many diverse topics fact or fiction.

When introduced to a new idea or subject that I find interesting, I enjoy researching more information about it, and talking about it.

WHAT IS A GANNET?



In case you're wondering, a Gannet is a big beautiful water bird that lives in large colonies on cliffs in the British Isles, New Zealand, and other places too. I was named after the bird.

I Am a Soundscape Artist, a Fringe Musician and Composer



I have a keen interest in sounds and music, especially keyboards - piano.

I am a composer, at work on producing CDs, and would love to collaborate with other musicians.

I listen to a wide variety of composers - especially exciting-dynamic music – from Steve Reich to Igor Stravinsky, from new music to jazz to classical and electronica.

Keyboard musicians are my favorites – from Bach to Thelonious Monk.

I like to attend live music performances – at clubs, concert halls or outdoors.

Music is My Vocation: A Life Goal: I want to keep adding to my music training and music making. The goal is to collaborate with other musicians to create CDs. I play the keyboards and synthesizer. I like to play alone and jam with others. The goal is to develop a group of people who are interested in making music with me. I would also like to collaborate with a studio sound artist / engineer, who can take my tracks and build upon them to create an album.

Music Gigs: I would like to have at least 4 performance opportunities a year.

Artists that I support



I have a kindred spirit with people like the art cars folks, the Thingamajig musicians who give concerts with their handmade instruments, the Sins Invalid theater company, specific musicians and street artists, etc. I go to their art exhibits and performances at local venues and clubs. I also like to collect art that speaks to me.

How I Look



I have worn a beard, and sometimes I'm clean-shaven.

I want to look hip and intelligent, and be dressed appropriate for the occasion.

I drool – my apologies – so keep a handkerchief handy.

I want to be clean, and not be seen with drool, food stains or dirt on my clothes.

What Makes Me Happy. What Makes Me Upset



I'm happy when. . .

I'm with people I really like and they take time to communicate with me.

I am understood, and my communication is clear.

I feel good about what I'm doing.

Playing music. Music is my feel-good vibe.

You notice I'm weary, and ask me if I want to take a break, and rest awhile.

I get upset when. . .

I can't communicate what I need, or intend to do. It's damn frustrating!

People talk down to me, or talk about me as if I'm not there.

People lead me around like a dog, talking to me but not expecting me to talk.

People baby-talk to me.

People take over my life, as if I'm an incapable invalid.

People feel sorry for me.

When I'm tired, and need a break.

And, sometimes the upset is inexplicable. It's like my brain has a switch, or has a chemical reaction or hot flash. I don't have control and I freak for no reason. Help me calm down, be patient, ask questions and help me transition.

Personal Philosophy & Values



This list represents the backbone of the lifestyle choices, philosophy, and values that I experienced growing up within my family. Friends and staff need to maintain opportunities that enable me to communicate and experience these lifestyle and ethical choices, and document new ones.

- Friends and family are very special. Have a big heart.
- Be a good neighbor.
- Have a social conscience, respect and tolerance for others.
- Volunteer for good causes. Little steps add up. Work for peace.
- Act responsibly. Be honest. Be responsible for yourself. Respect yourself.
- Live within your means. Be frugal, but spend some on frills too.
- Practice generosity. Don't be greedy.
- Exercise your freedom of speech when so moved.
- Obey most rules. But, question authority and power if it doesn't seem right.
- Equal rights for all people.
- Be good at what you do.
- Find happiness and fulfillment in your creativity. Offer something good back to your community and the world.
- Love and laughter go a long way.
- Be flexible and accommodating. Cooperation is a very good skill.
- Make intelligent decisions. Ask intelligent questions.
- Make change. Have patience for change.
- No religion.

- Act appropriately and you can go anywhere. Act inappropriately, and you need to leave.
- Be creative and broaden horizons through live music, art museums, performance arts, literature, different cultures, etc...this is the spice of life.

My Self-Help Skills and Abilities



This is just AN OVERVIEW

Note: Step-by-step descriptions of how I actually accomplish activities and tasks, and how staff support me, are available as Task Analysis videos and documents.

Doing it My Way – A Mixed Bag of Abilities

My self-help skills are mixed. Some things I can do totally independently. To complete some activities I need prompts and cues, and for others I need total assistance. I can be inconsistent - do something brilliantly one day, and not the next. Even if I can do something myself, sometimes, I purposely hesitate to see if I can trick somebody into doing it for me. So, BEWARE: in many situations, the more help you give me, the more helpless I become.

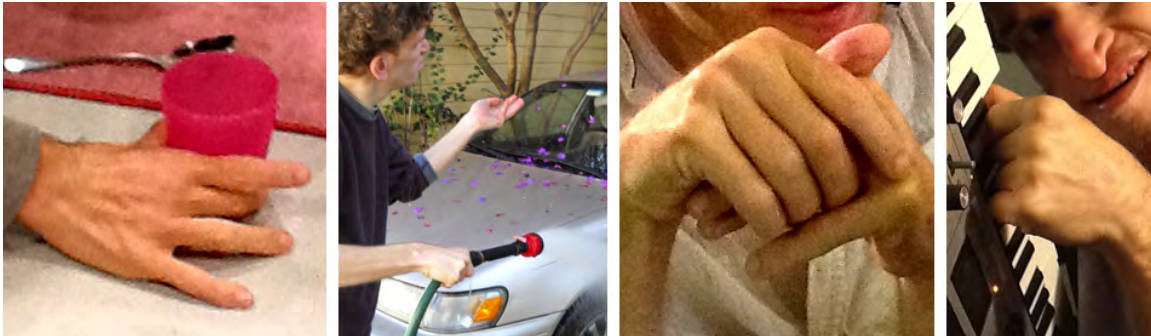
VISION



I've had cataract surgery in both eyes, and my visual acuity is now within the normal range. However, I am also considered "vision impaired" which has to do more with how my brain processes the vision. When asking me to look at something or to make eye contact, be aware that I tend to use my peripheral (side) vision, or I might look at something then look away before I reach for it. Sometimes, when you want me to look at something, or to read something, you

need to direct my attention, by moving the object or tablet, or use an animated point to lead my eyes, or tap on it to make a noise to attract my attention.

TOUCH and FINE MOTOR SKILLS



I never refined a lot of fine motor skills. Because of CP I use a slow, more “primitive” grasp with my fingers and palm. I explore things by tapping on them with my thumb or fingers. I do not like to hold on to objects (whether large or small) for long periods of time. I need these skills to perform tasks, so please encourage me to get better at holding onto and manipulating objects. Also, while I love having a pet at home and throwing sticks or balls for dogs, I do not like to pet animals or touch any soft fuzzy surface. I recoil.

COMMUNICATING



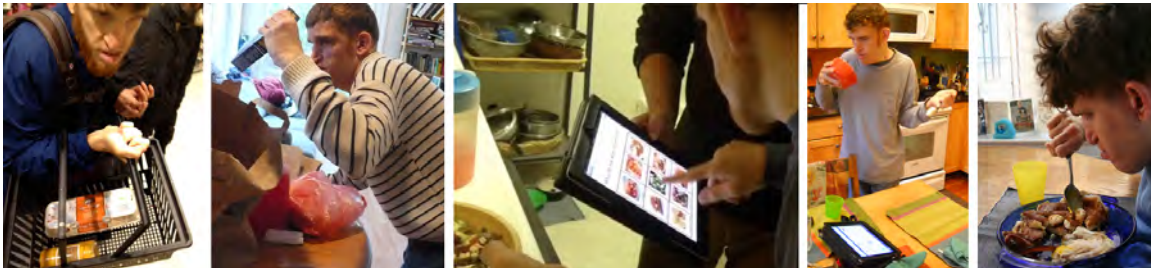
I have problems with instigating communication. I might vocalize sounds, or point, or grab your hand to lead you somewhere, but hardly ever walk to my iPad to use it spontaneously (*so, please, encourage me to do so more often!*). I usually rely on you to be proactive and get my iPad out, to ask me questions about what’s on my mind, or what I need at the moment. I understand everything you say, and I enjoy conversation. I can speak if you help me use the iPad communication apps. I point to and touch the icons that have a digital voice. I also point to words on the screen or words that you write on paper, will point to objects, and can lead you to people, places or things that I’m talking about. *More details are in the “How We Talk to Each Other” section, and task analysis videos.*

GETTING AROUND



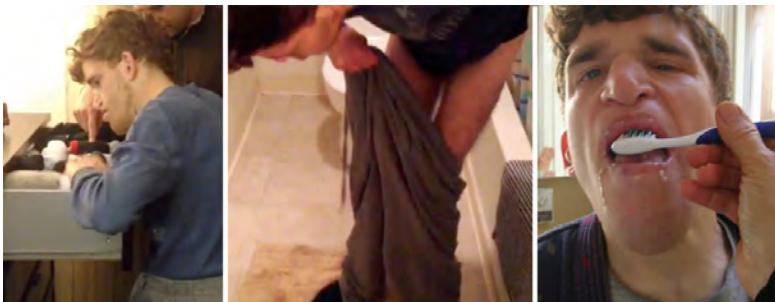
Inside the house, I'm totally independent to walk around, even up and down the stairs, wearing braces or barefoot. Outside, wearing braces, I prefer to hold on to a person or railing with one hand. On flat-even surfaces I can walk by myself. I have a lot of stamina, and can walk for miles – on a sidewalk, smooth hiking trail, the beach (especially bare foot in the surf), etc. **WARNING:** I can stumble on rough surfaces, sidewalk cracks, roots, etc, so I need your help to tell me about any bumps in the road, or when surface level changes.

PLANNING MEALS and EATING



Planning meals, shopping, and helping with food preparation are an important part of my weekly chores and daily tasks. With staff facilitation, I am semi-independent in many meal time preparation tasks - like getting groceries off the shelf and into the cart, getting food out of the fridge, choosing what to eat and how to cook it, and setting the table. I am learning new skills all the time. I can eat independently, but I do not spontaneously help myself to fill my plate, or refill my cup, rather point to what I want more of.

DRESSING and PERSONAL HYGIENE



With facilitation, I can gather my clothes and assist staff to put them on or pull them off. I need a variety of assistance in grooming and bathroom skills. I can independently turn on the water faucet, fill my glass and drink, put the glass down and turn off the water. With facilitation, I am also expected to try to wash my hands. If I am wearing elastic pants (like pjs or gym pants), I can take myself to the toilet to pee, with only a bit of staff oversight. Staff take over and do the following for me: empty and/or change my colostomy bag, brush my teeth, wash my face, comb my hair, give me a shower and a swipe of deoderant, and give me a shave (if needed).

HOUSEHOLD CHORES: LAUNDRY and CLEANING



With little or no assistance: I am expected to put my dirty clothes in the hamper, and can carry bundles to the laundry. I can fill the washer, and push the button on. You can add the detergent, and set the dials. I can transfer the clothes to the dryer, and pull them out when done, and help to put my clothes away. I have a tendency to fling the clothes, and stop working mid-stream to complain. Encourage me to finish the job.

I help rid up the apartment, and put things away, and can use a rag and spritzer to clean surfaces. I need encouragement to hold on to the objects and rag. At this time, I do not sweep, but I do windows.

GARDENING and WASHING THE CAR

I currently have a garden on my patio, and use a hose or sprinkler can to water it. I can also pull weeds. I help to wash mom's car. I use the hose to spray it off, and with assistance, will also use a sponge, or a spritzer and rag to help wash the car for brief periods of time - a job best achieved if we take turns and make it fun.

SURVIVAL SKILLS = NONE



IN THE EVENT OF EARTHQUAKE, FIRE, OR EMERGENCY

I need total hands-on assistance in an emergency. I cannot exit a building if an alarm goes off, nor do I follow verbal commands to do so. Staff is required to stay with me and assist. I am aware of hot surfaces, like the stovetop, and avoid them. However, if I am in a shower, and accidentally turn up the hot water, I will start groaning, but will not shut the water off, and cannot exit the tub. I do not catch myself if I fall or have a seizure, and will go splat. The good news is, I am very aware of my balance, and don't fall often. You need to be aware of all the dangers in my environment, and be alert.

NEVER LEAVE ME ALONE, UNATTENDED – ANYTIME or ANYWHERE!

You do not have to be on top of me, but ALWAYS BE NEARBY, WITHIN EYESIGHT OR EARSHOT.

EMERGENCY KIT

My apartment should have an emergency kit for first aid as well as a survival kit if we need to evacuate, or are stranded for a few days. Please get familiar where everything is.

EMERGENCY PLAN

Text and call my mother's cell phone: 415-238-1077, email ahosa@aol.com.

Mom's landline is 415-647-9119.

Out of state contact, is my Amah's cell phone at: 575-523-2950.

If Gannet cannot go home, and Mom's house is safe: 2759 22nd Street (near corner of Bryant St.

My Achievements



THE KEY OF G – A DOCUMENTARY ABOUT MY LIFE at Age 22-24

A documentary of my life premiered in San Francisco in 2007. I was invited to be a presenter in Rochester, NY at the Eastman/Kodak Center to speak to the audience after a screening, do a half hour radio interview (with the help of my dynavox), and did Q&A after a presentation at a special forum for local agencies, and educators.

THE KEY OF G tells the story of Gannet, a 22-year-old man with severe disabilities, as he prepares to move out of his mother's home and into a San Francisco apartment with three musicians and artists as primary caregivers.

Winner of the 2007 Golden Gate Award for Best Bay Area Documentary at the 50th San Francisco International Film Festival, **THE KEY OF G** follows this unique household over several years as the usual difficulties and joys of group living are heightened by G's unique condition. Through the difficulties, relationships deepen and G's world continues to expand. LINK <http://www.lateralfilms.com/keyofg/index.html>

ADVOCACY for PEOPLE WITH DISABILITIES



Alex and I WALKED 5 K for the Human Race fundraiser. This is the longest race I've ever done, and I finished last, but not least! I was very proud of making

it to the red arch at the finish line, as well as raising money for Casa Allegra Community Services.

When there were budget cuts, I joined Mark Melanson and ToolWorks friends to go to City Hall to meet with the State Legislatures in their home offices and spoke out for the rights of people with disabilities. I also march in parades, and attend rallies and community meetings.

MY TEACHER HONORED by Support for Families with Special Children



I'm very proud, that **MARK ERICKSON**, my high school teacher, was honored by Support for Families with Special Children as recipient of their annual honors award. I was invited to sit at Mark's table. The theme of the event was "A Night at the Prom." I was voted "**King of the Prom**" that night...much to my chagrin. I told my mom, that "yes" I was glad that people paid money to vote and that the votes helped to raise funds for the organization, but "no" I would not wear the crown.

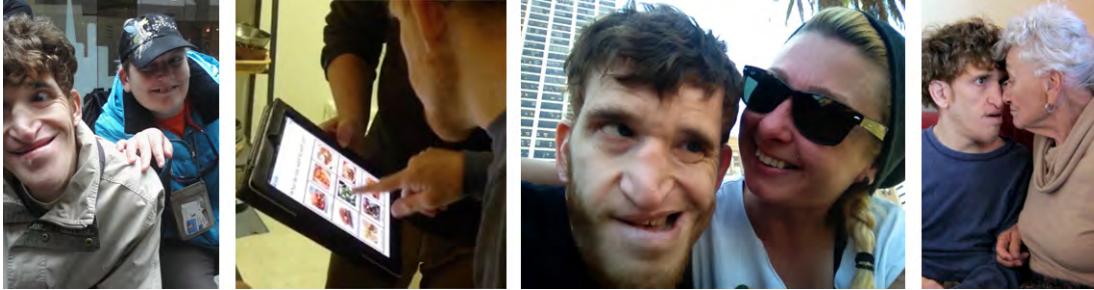
TAKIN' IT EASY – My First CD



My first CD, *Takin' it Easy*, was produced by Alex Gallego. "Thank you, Alex!" I'm working on new keyboard compositions and hope to collaborate with other friends and musicians to produce a new CD out late in 2013 or early 2014.

You can sample my music on my website: www.gannetsnotes.com

How I Communicate



How We Talk to Each Other

HOW I TALK TO YOU: I have problems with instigating communication. I might begin to vocalize sounds, or point, or grab your hand to lead you somewhere. I hardly ever walk over to my iPad to use it spontaneously. ***I rely on you to be proactive: to ask me if I want my iPad or to show you something, to ask me questions about what's on my mind – is it something general, or what I need at the moment.*** By using a variety of communication systems, I express words and articulate ideas. I will point to pictures, symbols and words to string thoughts together. I can be very specific. You need to be very patient. If we don't succeed in a clear communication, you need to alter the approach and try again. Note: A lack of spoken language is typical of people with Mowat-Wilson Syndrome.

HOW YOU TALK TO ME: I understand you. Please talk to me like an intelligent adult. Besides what you speak to me, I can read and understand individual words and picture symbols. You can also use the iPad apps, or you can write key words on a piece of paper to give me “communication tags” that I can use when I respond back to you about a particular subject. You might need to use a mix of these methods – draw a picture, use existing picture icons, written key words, photographs, pointing to objects, etc that help illustrate what you're talking to me about.

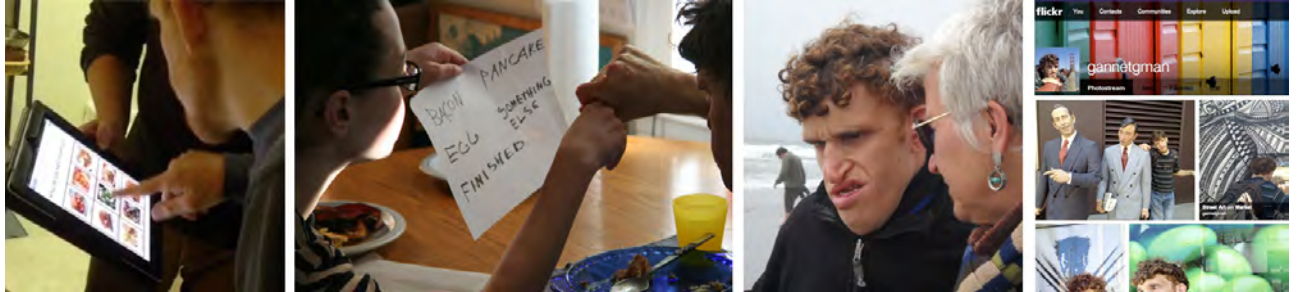
Everybody who works with me needs not only extensive training on my communication systems, but also training on how to interpret my conversations.

BEWARE of MISINTERPRETATION: The success of my communication depends not only on my choice of words, but also on their interpretation by you, the person listening. Sometimes my speech is cryptic, or confusing. *(YOU should try making intelligent conversation with just a few hundred symbols!)* Facilitating and interpreting my communication is complex, please have patience to ask questions and confirm intent, so you really get what I'm trying to say. *See the Task Analysis section: Communication.*

INCONSISTENCY: There are days when I am spot on, clear and concise in my pointing and choices, and others when I just flip the iPad away. It is sometimes hard to discern whether I'm simply confused and having a bad day, or I'm just

being pissy and uncommunicative; or whether I am frustrated with you for not understanding my intentions; or frustrated because my book does not contain the words I need to say.

SEE THE TASK ANALYSIS VIDEO FOR EXAMPLES OF HOW-TO



An Overview of My Communication Systems:

iPad APPS for PICTURE COMMUNICATION w/VOICE and WRITING WORDS (*All communication apps are under one button on G's iPad main menu*): My primary communication tool is the ProLoQuo app that displays icon lists on the iPad touch screen with digital voice output. You can also use the touchscreen as a tablet for writing down word choices or questions with apps like DigiDraw. Other apps I use are specialized for storytelling, like Pictello. **I expect these apps and communications to grow with me, and be constantly updated to reflect my life and needs.**

VOCALIZATIONS: “Achoo,” “buh” and “mumum” are the main three words that I speak, and they have many meanings depending on the situation. For example: “achoo” can mean “hello”, or “I love you”, it’s also a repetitive happy banter back & forth between myself and others. “Mumum” is a happy sound. “Buh” is used as a comment to let you know I’m present, actively engaged to the conversation, and responding. Growling means I’m pissed off.

TACTILE SIGNING: Tactile signing means that I grab your hand or finger and make a motion with it. I use tactile signs for: “yes”, “no”, “all done”, “get up, I want your help”, “I want that”.

POINTING: I will point with my index finger or tap on something with my thumb to make a choice.

GESTURES: Patting someone’s arm or shoulder is my customary greeting “hello”. Foot stomping means, “I’m pissed”. This is how I say “Help Me!” when something is wrong, or I’m sick or emotionally upset or tired using any or all of the following gestures: I hold a hand to my forehead, bang my head hard on you or a wall, slap my face, or bite my hand, or growl.

FACIAL EXPRESSIONS: You can't read my lips, but you certainly can read my facial expressions to get a clue as to what's on my mind.

LEADING: After I pull your hand or arm to say "get up, help me", I'll lead you to what person, place or thing that I want.

PHOTOGRAPHS: Photographs are my memory bank. Sharing photos (stored on the iPad as well as in digital photo albums at Flickr) is the best way to tell my friends and family what I've been up to. I also love to look at my photo albums now and then, just for the sake of reminiscing.

How I Want YOU to Interact With Me

Different Levels of Support and Care

Upon first meeting me most people make the mistake that I'm helpless, and they treat me like a simple-minded invalid. Let me cut to the chase and give you some definitions to enable you to interact with me as an intelligent, capable and semi-independent person, who needs different levels of support and care depending on the situation.

Definitions of Facilitator, Assistant, and Caregiver

To facilitate is "to make something easier, or easy to do".

A facilitator "aids or assists in a process, especially by encouraging people to find their own solutions to problems or tasks".

To assist is "to help somebody to accomplish something".

An assistant "helps somebody do something, or takes charge of some aspect."

To give care is "to take responsibility for a personal need" or "give comfort."

A **caregiver** "offers assistance and comfort, and makes life good."

You need to remember, I take pride in my abilities and accomplishments.

Too much "assistance" and "caregiving" when I don't need it, makes me helpless and angry. The LESS you do for me, the more independent and successful I am in living my own life.

Your Roles: Hands-Off, Facilitator, Assistant, Caregiver



1. Hands-Off



2. Facilitator



3. Assistant



4. Caregiver

1. You can be HANDS-OFF

When you allow me to be independent and take whatever time I need to finish the task by myself. This is harder for you, than it is for me. Have patience!

2. You are a FACILITATOR

When you offer me encouragement, giving me cues, or teaching a skill.

When you set up a task to make it easier for me (which still might take me 30 minutes to accomplish it as independently as I can), rather than you taking control and doing it for me in 2 minutes, because it's easier for YOU.

This empowers me to have control of my actions and life, on my own time!

3. You are an ASSISTANT

When I need a hand, or because the task is beyond my abilities.

Your assistance might be a light touch for only a second or two at the critical moment, or it might be hand-over-hand to help me complete the entire task.

4. You are a CAREGIVER

When you totally do something for me like cooking and cleaning, giving me a shower and my meds, or taking care of me when I'm sick.

5. You are a DEAR FRIEND

When you do a mix of ALL of the above...and you have patience to allow me the time to be independent to the best of my ability as it varies from one situation to the other. It takes more time, creativity and effort from you, for you to be a facilitator and assistant...but that's the only way that I get to live my life.

Please remember, that although you might think you are being nice to me and making my life easy by doing everything for me and letting me just kick back - that is NOT your job description, and that is NOT how I want to live my life.

My People and Circle of Support

My Family and Friends

I have family and friends in San Francisco, and like to stay in contact with them. A contact sheet (with names, emails and phone numbers for family and friends and emergency contacts) is in a separate, private document.

Family



My **mom, Amy**, and her partner **Chris** live in San Francisco. We try to see each other about once a week. Sometimes mom comes over after work for dinner and we might also walk to a jazz bar to hear music. Sometimes I like to stay at mom's house overnight on weekends for a change of scene. **Amah, Flo**, lives in New Mexico, and I like to talk to her on the phone. **Dad, Robert**, does not have a permanent residence and is retired and travels, so I see him infrequently.

People I Hang With – My Friends



Leroy (aka my brother) lives in the East Bay. We lived together for 6 years when I was in high school, and he's like my brother. Leroy is a spoken word poet and actor in a theater group Sins Invalid, and I never miss a performance. Some of my staff and old teachers have become good friends, and I really enjoy spending time with them as buddies...like Alex, Bennett, Ryan and Jake...just to name and picture a few (the entire list is on the contact sheet). We have dinner together, go to an art opening or museum, go to a bar and listen to music, go out of town, catch a movie or a concert, go swimming, kayaking, camping, etc...

Staff and Old Friends – People I stay in touch with...



There are a number of people who I don't see often, but I keep in touch with – they're old teachers, ex-staff, and old family friends – like Jim, Donal, Amanda, Robert, Colter and Mark. When there's a holiday I like to send them a greeting. If I have a party, I send them an invitation, and sometimes we just get together for dinner.

Peer Friends from Activities – My Buds



One of my goals is to make and keep friends who are my peers – like Jerome who I see at Enchanted Hills Adult Camp every summer. Rachel is in ToolWorks with me, and we've known each other over 15 years. Charlie, now lives in Santa Cruz, and our moms also are best friends. I like to invite my friends to my parties, like Rachel, Jenny and Carson. At ToolWorks, I prefer to do activities with my friends in the group.

Best Friends



I like to visit Josh or Charlie on weekends. Josh is also a musician that I jam with. I want to thank Alex for making our visits happen!

Music Nights at My House with Friends



I also have friends who share my interests in music and I invite them over for dinner and to jam. Alex is an amazing guitarist and my mentor. He jams on the guitar, and he helps me to lay down tracks. We collaborate on compositions to create CDs using his software. My friend Josh jams with me, and occasionally Colter and Donal.

Community Friends



A lot of people know who I am and say hello on the street and chat – like some of the musicians at the Saturday Fillmore farmer’s market and the produce vendors, the artist Duke who lives down the street (and whose art I collect), wait staff in my favorite local restaurants and nightclubs, store clerks, bus drivers, neighbors, etc (a full list of names and places is in the “My Neighborhood” section. Please get to know who they are, and help me say hello, and have a short conversation with them. Ask their names, so we can say hello back to them next time.

Others: Service Agencies, Camp, Doctors, etc.

SUPPORTED LIVING SERVICES: Casa Allegra (CACCS)

Socorro Gallardo, Director of Supported Living Services

Alex Gallego, Coordinator and Live-In

Link to CACS: www.casaallegra.org

DAY PROGRAM: ToolWorks

Sarah Hillen, Director of Day Program

Bennet Tgalio, Coordinator

Link to ToolWorks: www.toolworks.org

CASE MANAGEMENT & FUNDING: Golden Gate Regional Center

Stephanie Karim, Case Manager

Don Cornejo, Supported Living Services

Link to GGRC: www.ggrc.org

CAMP: Enchanted Hills Camp

Run by the Lighthouse for the Blind

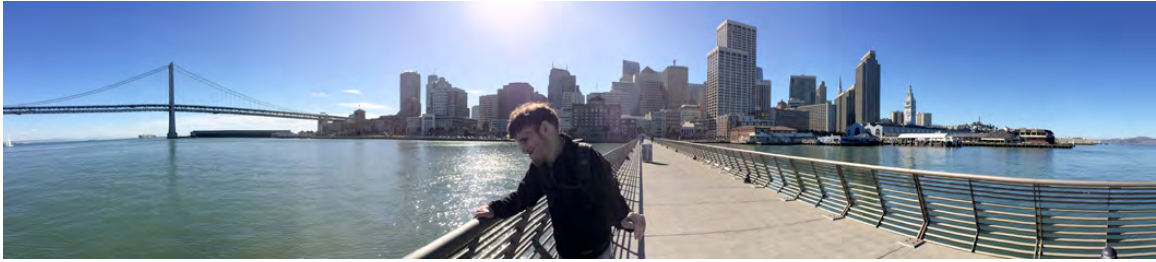
Sign-up is online. Keep Checking in January. It fills up FAST!

Link to Enchanted Hills Camp: <http://lighthouse-sf.org/programs/enchanted-hills>

MEDICAL: Kaiser, San Francisco is Gannet's main health care provider

Alex Gallego has authorization for access to medical information and to take him for treatment.

My City, Neighborhood and Home



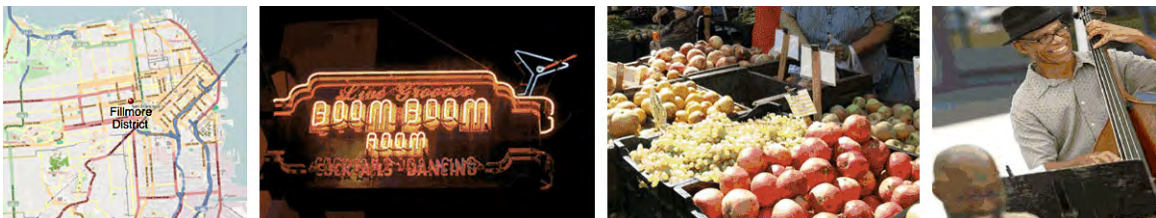
San Francisco is My City

I like to be out, and love the sounds and motion of living in a city. I love the energy of it all.



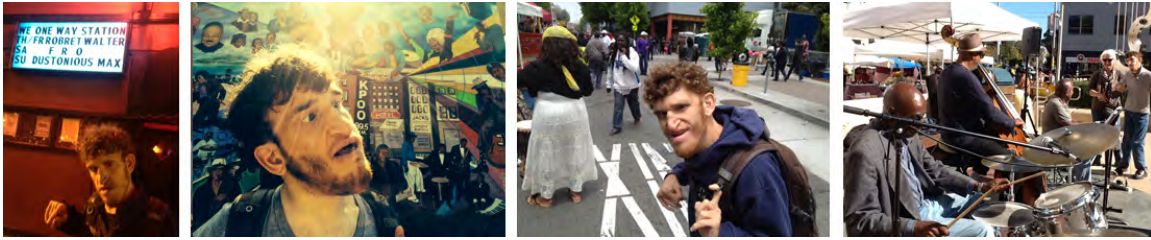
I like the adventure of riding on public transportation - the busses, streetcars and BART. I like the variety of places to go in the city – like going to a museum or walking in the cold surf on a beach or having a picnic in a warm-sunny park, or even just getting out of the house to run an errand to a store nearby. I enjoy going out to all the free concerts, street fairs and events. I also have memberships to both fine arts museums, the DeYoung and the Legion of Honor, and go to evening adult events at the Exploratorium and other venues. Just about any month, there are concerts and events given by folks that tickle my soul, like the Thing-a-ma-gig music makers, or Street Dancers and Pamela Z. San Francisco is a great place to live, and a great place for me to pursue my music and art too. In San Francisco, there is no excuse to find me sitting at home because there's nothing to do!

The Fillmore is my Neighborhood



I live in a huge apartment complex in San Francisco's Fillmore District. I prefer to live in an urban neighborhood that is alive, and has all the amenities within a short walk, like bus stops, grocery stores, restaurants and general shopping. The Fillmore neighborhood has all the above, plus a recreation center with swimming,

music and jazz clubs, parks, an open-air farmer's market and more - all within 2-3 blocks. Even my doctors' offices are only a 6-block walk away. The neighborhood is fairly safe, yet we keep our street-smart senses alert.



SOME THINGS I ROUTINELY DO IN THE NEIGHBORHOOD

I like to plan my daily menu, so many afternoons I take a walk to buy something to cook that night. Occasionally I will to eat out, and will choose a nearby restaurant or cafe.

I like to hear music and have a soft drink at the clubs, like the Boom Boom Room or a jazz bar. We go on the early side, before it gets too crowded.

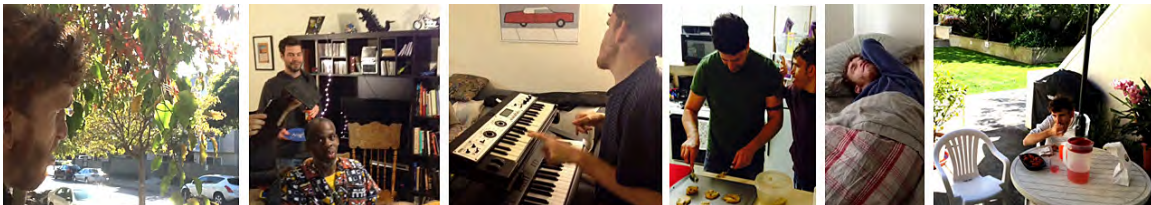
With the iPad, I shop at the Saturday Farmer's Market, and chat with the vendors, then listen to the free jazz combo on the plaza.

I prefer the warm pool at RCH, but the neighborhood pool a few blocks away can be a destination of choice on a hot day.

I like to catch a movie at the Kabuki/Sundance Theater now and then.

Note: While I love going out, I sometimes do not like to be in over-crowded spaces, or loud noisy venues with crowds of people milling about. If I get agitated at a club, or at the farmer's market, please take me to a quiet spot and ask me tell you what I'm feeling and need at the moment.

Feeling at Home in my Apartment



I'm very lucky to have a 2-bedroom apartment with its own patio that connects to a big common courtyard. My apartment is decorated with artwork and photography of my choice, and things that express my personality and taste.

There are many things that make me feel at home: a nice dinner, my music, my favorite truck (spinning wheels), opening and closing the dishwasher, knocking on the walls, an occasional movie or special program on tv, an afternoon snooze in my comfy bed, and of course playing my piano and keyboards.

These situations do not make me feel at home:

I do not watch TV much, do not prefer it as a regular pass time. If you are working with me, do not assume that I want to watch your favorite tv shows, or listen to your music. I also don't like people who support me to spend time on their cell phones or computer conducting their personal business.

My habits and rituals

There are a couple of things that I must do at least a couple of times a day. They include opening and closing the washing machine door, as well as, the refrigerator. Knocking on the wall of the bathroom, and turning the kitchen lights on and off a number of times.

Favorite Foods



A NOTE ABOUT NUTRITION:

Because I have a colostomy, nutrition has always been an important consideration in food preparation. I have always eaten **well-balanced meals** prepared from **fresh foods** – very little canned, frozen, or processed products. However, if we slip out for a fast-food meal on occasion, a good taqueria or pizza or Chinese place is my suggestion (not McDonalds, etc).

RECIPE BOOK – Gannet's Favorites

I don't cook, but I can help get out the ingredients and I love to supervise. Staff and mom are helping me compile a recipe book of my favorite foods. I'll eat just about anything – including all kinds of salads! I have a big appetite and can eat 4 helpings. I have no allergies to food. I do not drink milk, but I love other milk products like yogurt, ice cream, cheese, etc.

MEAL PLANNING: Here are some of my favorite comfort foods.

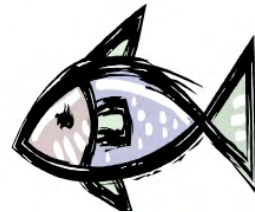
For breakfast



I usually like sunny-side-up eggs, or a scramble with some cheese, onion and tomato, and some breakfast sausage, and if there is time for home-fried potatoes, I won't say no. I also like to have oatmeal and cream of wheat. To change it up, I also like granola cereals with yogurt or milk, a banana and berries. Sometimes I enjoy a fruit salad but not always. At mom's, I frequently ask her to make French toast with syrup and jam, or pancakes with sausages. FYI: I, however, do not care for really hot cereal unless it has had a chance to cool down a bit.

For lunch, if not home, I either bring a bag lunch (sandwich or leftovers), or I stop in smaller cafes to eat.

For dinner



Foods that make me feel like home are usually comfort foods such as lasagna, spaghetti bolognese, a roast chicken with potatoes, and burgers grilled on my patio. I also like fish and seafood, but I have been known not to like it too. It's all in the recipe. I also like sides of fresh cooked vegetables and green salads with home-made dressings. I love spiced and ethnic foods, but I do not like overly hot-spicy or hot-temperature foods. If you make soup, please add croutons or rice to give it some body. I don't like to eat liquids with a spoon!

Variety is the spice of life. It's important to mention that the dishes aforementioned are my "comfort foods." I am open to try new dishes and do love ethnic cuisines, so please cook up something yummy like an Indian curry, or Chinese stir fry, or an Irish stew.

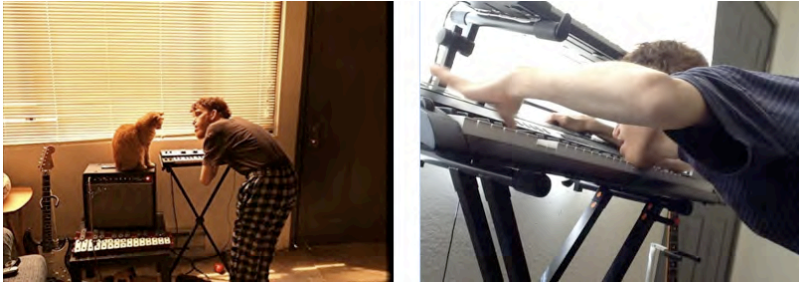
For desert, if it's cake, pie, ice cream or a chocolate desert, I'll probably love it!

Restaurants and Cafes



I love to eat out for lunch or dinner, as long as my budget allows. I like diversity, so ask me what I'm up for – Indian, Italian, Mexican, Thai, Chinese, American, savory spicy, etc. I appreciate if you help me keep my face and tabletop neat, if I'm a bit messy. Help me say hello to my favorite wait staff, and please tip.

Making My Own Music



Playing music, is my favorite activity when I am at home. I will walk right to my keyboards and start playing. I have a very sophisticated system that allows me to compose and play different keyboards to record my music. I love playing over jazz tunes or electronic music, and layering sounds. I am very creative and my playing shows it. I am not limited to keyboards to play music. My iPad has many music apps that can be played through the amplifier and generates totally amazing sounds.

Jammin' with Friends

I love to improvise with other musicians. I can change my keyboard synthesizer to be all kinds of musical instruments, even percussion. They can play the keyboards with me, or choose another instrument or iPad to jam.

For listening, I have a playlist of favorite songs – from classical to jazz to modern to pop.

My Patio



I enjoy spending time on my patio. Twice a week I water my plants with a hose or watering can, and it is fun. I have a grill and can help with cooking. Some days we eat outdoors as well, and maybe even play a game of ball or catch. Sometimes after dinner, I like to walk to the fountain and hear the sound and watch the colors in the water. It is relaxing.

At the End of the Day



When I start to get sleepy, I will grab my **yellow truck**. I love spinning the wheels, and feeling the vibration. It's relaxing and a nice prelude to a going to bed. Once in bed and as I drift off, I like to listen to **music**– I'll pick out a CD for you to play. I also enjoy listening to **a good book**, and hearing a chapter or two will do as I fall asleep.

Vacations, Holidays, and Celebrations

Heat Alert

If I go somewhere hot, please note that I do not regulate body heat very well. We do not have to stay indoors, rather keep a water bottle handy for frequent drinks and cool me off with a water sprayer or wet cloth, take breaks in the shade, or take me swimming. Sun is ok with sun-screen, so don't keep me "white" and totally covered up.

Camp and Recreation



Summer Camp at ECH – The Place to Be!

I LOVE summer camp at Enchanted Hills. I attend the "Adult Special Needs" session along with one or two of my supported living staff who provide 24/7 services. I've been going since I was a kid, and have many dear friends within fellow campers and staff.

I expect to go every year, do not miss the deadline for registration!

Link to Enchanted Hills Camp: <http://lighthouse-sf.org/programs/enchanted-hills>

Lighthouse for the Blind on Van Ness in SF, is the camp's home office.

Sign-up is online. Keep Checking in January. It fills up FAST!

Vacations - Getting Out of Town



I enjoy a road trip - getting out of town for a day, or a week. I like tent camping or a cabin, and being out in nature, floating on an inner-tube, hiking, riding on a kayak, being lazy, campfires, gazing at the moon and stars. I'll also settle for a motel or hostel. Being somewhere new, and exploring is right up my alley...just do not take me mall shopping!

Flying Anywhere

I totally love flying in an airplane and having a window seat.

Mom's House, and Family Vacations



I enjoy going to Mom's house for an overnight. It could be just hanging around the house and washing the car, or taking a walk on a beach, or a visit to Chris' boat or a museum! We all try to take one or two little vacations out of town a year, as a family, too. *(Note from Mom: Gannet is welcome to call and setup a visit or stay overnight at my house, as he enjoys the comforts of being "home" and especially being spoiled as a guest.)*

Major Holidays



Note from mom: Gannet's family celebrates holidays with no specific religion. We spend time with friends to celebrate the holiday or the changing of the seasons with decorations and special foods, give thanks, and make a wish for peace and goodwill, love and laughter.

For **Christmas and Thanksgiving**, I am usually invited to mom's house for 2-3 days.

For **Halloween**, we have a family carving tradition. I get my own pumpkin, and draw the face on it with a marker. Someone else carves it. You do not want a knife in my hands. I love to turn off the lights and see it glow in the dark.

Easter is usually a picnic in a park.

Many **3-day holiday weekends**, I'm invited to stay at mom's house for an overnight or two, so staff can have the holiday off.

4th of July – I may or may or may not be up for fireworks, or a big crowd.

Birthdays



I love to party with friends and family, and be the center of it all.

My favorite is a BBQ with all the fixings. Favorite cake is from Dianda's Italian Bakery at 25th & Mission: a rum cake or honoraria cake. If not, just about any cake & ice cream will do.

My Birthday is August 3, 1981

Giving Presents and Sending Cards

PRESENTS: Birthday and Christmas. I buy presents for family: Mom, Chris, Amah, Dad and Leroy, and any friends and staff that I choose. These are all small gifts, but items that I pick out. This requires pre-planning: Using my communication system, try to help me decide some of the choices for presents before we go shopping. Some years, everybody gets the same thing, but I choose who gets what color. Some years I choose a theme, or store or department, then I make individual choices for each person on site or online.

CARDS: Happy Birthday, Merry Christmas, or Happy New Year are sent to friends and family (see Circle of support list for dates and addresses). Staff have used online card shops to make me personalized cards with photos I choose for my annual holiday (Christmas/New Year's) card.

BONUS: Happy New Years Card to Staff. I give an annual bonus and thank you card to all staff with best wishes for a new year.

Supported Living Services for Home



Casa Allegra Community Services

With assistance, I chose Casa Allegra Community Services (CACS) to manage my Supported Living Services for day and overnight support in my home and household management. Casa Allegra has a Director of Supported Living Services and my household has a Coordinator, who is also my live-in, who manages my household, and assists in hiring, supervising and training my SL staff. The Coordinator manages and updates all my communication systems, photo albums, and training videos and guides. The Coordinator also interfaces with the ToolWorks Day Program coordinator and staff to ensure that my life is consistent and feels seamless between the many staff supporting me, and that the two agencies are on the same page. Every year we have one annual meeting with both agencies and staff to review to develop ideas for the Individual Personal Plan and IPP. The coordinators and staff of both agencies also meet ongoing for training, updates, and whenever there is an issue.

Music is my life goal for my vocation, and supported living services staff help me integrate my music, composing, recording, and performing into my home life with friends and out in the community to listen and perform.

I have many staff, and request that they receive training and support so that everybody is on the same page with me in how they support me to live my own life. If my needs are not being met, I have the right to ask management to intervene to remedy the situation or to hire someone who can meet my needs.

A Caregiver's Perspective:

Working with and for Gannet as a coordinator/caregiver/facilitator has been and continues to be both challenging and very rewarding. As with any other human being, Gannet is a complex, intelligent, free thinking, at time stubborn yet flexible, and, above all, goes through the same emotions we all experience. In other words, Gannet is like anyone else.

In my experience, one of the biggest mistakes one can make while working with Gannet is to believe that he is a two dimensional being and worst off all "hard wired" with no room for change or improvement. Nothing could be further from the truth. In fact, over the years, Gannet has learned many new skills that he applies to his daily life and has shown great open mindedness and adaptability in new environment settings and activities.

The most challenging aspect of working with Gannet is and probably always will be how to give him the opportunity to lead his own life and, therefore, we, as caregivers/instructors, facilitate his own choices and decisions without doing it for

him. This is difficult since Gannet might not always want to make the decisions and might not be forth coming in communicating with you. I truly believe that in order to be efficient when working with Gannet, one needs sometimes to step back and analyze what is being done and how it benefits Gannet.

Working with Gannet is personally very rewarding. Meeting goals and objectives, no matter how small or seemingly inconsequential, are in many ways great victories for Gannet and yourself that set the bar even higher for the next accomplishment.

CACS Contacts for Supported Living

Socorro Gallardo, Director of Supported Living Services

Alex Gallego, Coordinator and Live-In

Link to CACS: www.casaallegra.org

Golden Gate Regional Center – Case Management, funding agency.

Stephanie Karim, Case Manager

Don Cornejo, Supported Living Services Coordinator

Link to GGRC: www.ggrc.org

Sample of Supported Living Services (SLS):



This Person Centered Plan covers how I want to live my life, and the following are examples of some of the typical activities that are part of SL services.

On a typical weekday I am ready to leave the house at 9am. I return at 3pm and take care of any business then take a nap for 1-2 hours. I choose what I want to eat for dinner, and shop for anything we need, then help with setting the table and getting food out of the fridge. After dinner I might play the piano for pleasure or have a recording session, or go out for a walk, stop at a bar or café to listen to music or visit friends. I might even be cajoled into doing a few household chores like laundry or gardening. I fall asleep between 9 and 10.

Saturdays We usually go swimming at The Janet Pomeroy Center in the morning, and have a big brunch afterwards. We might pick up a few things at the Farmer's market and listen to the jazz combo, take a day trip out of town, or invite a friend in to play music and stay for dinner. I take a nap around 3 on weekends too. Evenings we might go to the movies, or go out to hear live music. Sometimes I stay overnight at my mom's on a Friday or Saturday night.

Sundays I'm ready to go out the door at 10am. It's a free day and can be spent hanging out in a park, going to a movie, special events, music, visiting friends.

24/7 Personal and Household Support, and Safety

SL staff are my lifeline, without them I could not survive! My staff take responsibility for all the necessities of my independent living, like keeping my communication systems up to date and taking timely care of business and reports for my section 8 voucher, IHSS and social security updates. SL staff help me stay healthy and take care of me when I'm sick, and manage my doctors appointments. They pay the bills, clean my house and do the laundry. They monitor my nutrition, go grocery shopping and cook me delicious meals. They take me shopping for clothes and household items, in addition to scheduling repairs. They keep my social calendar, coordinate visits with friends and family. When I have question or want to learn more about something, they help me find answers and more information to broaden my horizons. My staff listen to me when I want to talk about how I feel and assist me to express that to others. I'd be lost without Alex, my household coordinator and live-in, and all the support staff working with me.

Day Program Services for Work and Life Skills



ToolWorks

With assistance, I chose ToolWorks (TW) to manage my Day Program services. I participate from 9am to 3pm on Monday thru Friday every week. I like to do things with my peer friends, although a few activities are of my own special interest, like the music classes, and I go off to join other groups for that. I am one of their 1:1 clients. Every year we have one annual meeting with both agencies and staff to review and develop ideas for the Individual Personal Plan and IPP. The coordinators and staff of both agencies also meet ongoing for training, updates, and whenever there is an issue.

I have many staff, and request that they receive training and support so that everybody is on the same page with me and how they support me to live my own life. If my needs are not being met, I have the right to ask management to intervene to remedy the situation or to hire someone who can meet my needs.

ToolWorks Contacts

Sarah Hillen, Director of Day Program

Bennet Tgalio, Coordinator

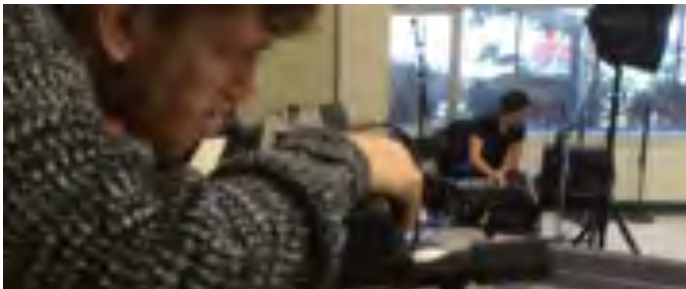
Link to ToolWorks: www.toolworks.org

Golden Gate Regional Center – Case Management, funding agency.

Stephanie Karim, Case Manager

Link to GGRC: www.ggrc.org

My Life Goal at TW: Music is My Vocation



I am a composer, fringe musician and soundscape artist. I have asked ToolWorks to work with me to create a plan to assist me to attain that goal. I want to keep adding to my music training and music making. The goal is to collaborate with other musicians to create another CD in the near future. The goal is to develop a group of people who are interested in making music with me. I would also like to collaborate with a studio sound artist / engineer, who can take my tracks and build upon them to create an album.

Music Gigs: I would like to have at least 4 performance opportunities a year.

Self Advocacy at TW



I participate in self-advocacy sessions at the office, and go to town hall meeting and demonstrations. I need prep-time before attending a session or rally, to work with staff to create a conversation page for topics that I wish to bring up. I have also met with local and State legislators, and am proud of my efforts and ability to be a spokesperson for my community.

Sample of My Weekly TW Schedule - from 2013

Note: The current weekly schedule and chart is available online to staff.

MONDAY - MUSIC CLASS



Gannet meets Jesse (regular staff) at his home at 9:00 am. They travel to the ARC on the 31 bus heading into downtown and transfer to any route that moves south down Market, getting off at or around 11th St.(see fig.1) From there they walk to the ARC to meet with other Toolwork groups for **Music Class** which starts at 10:30 and ends at 11:30. In class, Gannet works on improvising, re-creating, composing, and listening to music.

Goal areas include things such as improving communication skills (expressive and receptive), improving motor function and coordination (both fine and gross motor skills), developing and improving social skills, modifying behavior and addressing emotional needs and self-expression. Gannet has his own keyboard that stays in class, secured in the ARC's offices.

After class, staff and Gannet discuss where to have lunch. The library has become a popular choice due to the close proximity and G's liking to the library café's Chef salad w/ spinach. After lunch, Gannet will often take a walk towards the Embarcadero where he likes to play ball with staff and/or catch up with staff using his his communication apps on his iPad.

Peers: John, Maggie, Yah, Vladimir, Lock Mei, Bruce, Barry, Michelle, Francisco, James

Locations: The ARC, 1500 Howard St. @ 11th (SOMA), (415) 255-7200

TUESDAY – COOKING CLASS



Gannet meets Jesse (regular staff) at his home at 9:00 am. They travel to Safeway in the Castro on the 22 bus and get off at corner of Church and Duboce for Cooking Class. From there they walk to Safeway and meet up with the group.

The group then discusses the day's meal and delegates items to buy to each member in the group.

Goal: G will then shop for 2-3 items. The goal here is to locate and obtain items in the store, and take them to the cashier and pay.

After shopping, G and the group take the F train down to 6th and walk to Bayanihan on Mission to cook and eat lunch.

Goal: G helps with some preparation of the meal such as setting the table and washing vegetables.

After Class: The combination of grocery shopping and cooking take up most of the day so after lunch, G will walk towards the Embarcadero to catch the 31 bus back home.

Staff: Jesse, Michael

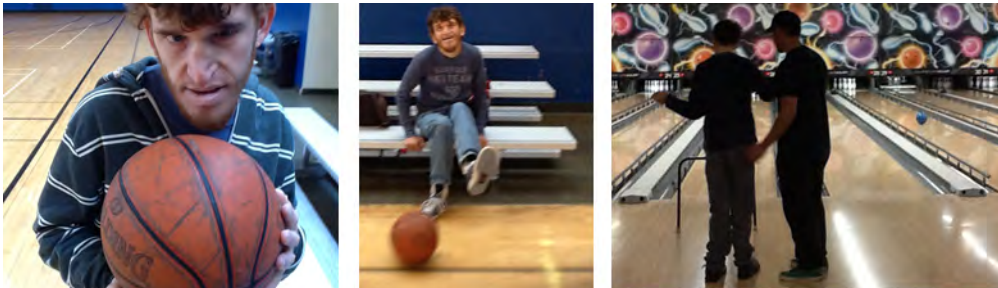
Peers: John, Kevin, Katherine, Frankie

Two Locations:

Shopping: Safeway, 2020 Market St @ Church (Castro), (415) 861-7660

Cooking: Bayanihan Community Center, 1010 Mission St @ 6th , (415)348-8042

WEDNESDAY: Gym and Bowling



Gannet meets Alex HW (regular staff) at his home at 9:00am. They will start the day with a walk to the Hamilton Recreational Center where they spend the morning playing basketball.

Goal: G works on throwing, catching, and kicking the ball developing his hand and eye coordination.

After class: After some time at the gym, Gannet and staff determine where to eat for lunch. The choice of eating someplace downtown is preferred in order to be near the afternoon's activity of bowling at the Yerba Buena Gardens. After lunch, Gannet joins other groups at Yerba Buena Bowling Alley for one game.

Peers: Vladimir, David, Francisco, Maggie, Michelle, Bruce

Locations: Hamilton Rec Center, 2005 Post St @ Steiner (Western Addition)

(415) 292 – 2111; and Yerba Buena Bowling, 750 Folsom St.@ 4th (SOMA), (415) 820 – 3540

THURSDAY - MUSIC CLASS



Gannet meets Bennett (regular staff) at 9:00 am at his home. They take the 31 to downtown and take BART to the ASHBY BART station in Berkeley to attend **Maya's Music Therapy**. The class starts at 10:15 and goes until 11:30. During this time,

Goal: Gannet works on improving his communications skills, developing and improving social skills, modifying behavior and addressing emotional needs and self-expression. Gannet uses his iPad and its many music apps to contribute to the session as well as listening to new music from others. This session is different from his Monday's Music Class in that there is more personal one on one time with the therapist.

After Class: After Music Therapy, Gannet and staff discuss options for lunch. The nearby restaurants and ERC café are great choices and then eating at the Ed Robert's Campus outside on the decks. After lunch, Gannet and Bennett take advantage of the time in the East Bay by choosing an afternoon activity in Oakland and/or Berkeley. A walk around Lake Merritt, a visit to the Oakland Museum, or the many art galleries around the East Bay are some of the activities Gannet embarks on. Around 2:00 pm, Gannet and Bennett make their way back to San Francisco.

Peers: Claire, Orion, Sam, Gary

Location(s):

Ed Roberts Campus, 3075 Adeline St. in Berkeley, (510) 649 – 1322

FRIDAY - OPEN CHOICE DAY



Gannet meets Bennett at his house at 9:00 am. Friday is reserved for any activity Gannet decides upon. There is a loose schedule of going to the SOMA Rec Center to attend Disco Fridays and/or volunteering at Hyde St. Pier and wiping down the vintage automobiles. Being a member also allows Gannet to go to the Legion of Honor in the Presidio, the De Young Museum in Golden Gate Park, and the SFMOMA in the Financial District for free and allows an

opportunity for Gannet to check out new shows and exhibits. Another option for Gannet is watching a movie at the Century Theaters in the Westfield Mall downtown. At the Century Theaters, a former staff has arranged a lifetime pass for Gannet to watch any movie for free. His regular staff, Bennett will also take the opportunity of the open schedule and work with Gannet tagging, labeling, and editing photos from the previous days.

History of Volunteer Jobs and Skills



Detailing Cars and Motorcycles

These jobs occurred at: **The Scuderia**, a motorcycle shop, for 7 years; the **Hyde Street Pier** antique car collection, for 6 years; and currently Mom's car when I visit on weekends. I have an avid interest in cars and motorcycles. I am learning to use a spritzer bottle and rag, and use a hose with spray nozzle. Part of the job activity includes taking breaks to learn about different mechanical parts and identifying logos. FYI: Although it requires the same skills, I have absolutely no interest to clean tables at a fast food restaurant. *See task analysis.*



Gardening

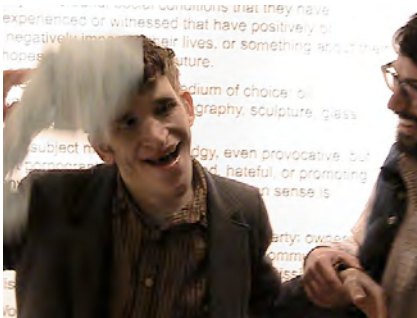
I have my own garden at home. Gardening jobs have been at the Central YMCA, and local community gardens. I also help maintain the flower garden on my patio at home, and mom's vegetable garden: I gather the tools needed, water with a hose, pull weeds, harvest, and carry the compost to the bin. *See task analysis.*

Recycling and Collecting Things



I've had jobs at home, at Kezar Recycling Center, and at the Maritime Museum office. I gather a light load of recycling into a container (with hand grips or hand holds), and carry it to a recycling bin to dump. Glass recycling at Kezar was exceptionally worthwhile...to hear the noise made by breaking glass. I also worked at a thrift store collecting empty hangers off a rack, and carried them to a bin. The payoff was the sound the hangers crashing into the bin. See task analysis.

Music Gigs



I have had the opportunity to play with friends and solo at a coffee houses and art openings. I take my synthesizers and speakers. I definitely take it seriously, and understand about having stage presence. I played an original composition for my first performance at the annual Maya's Music class recital in 2014.

Jobs I Do Not Care For

Jobs that require fine motor skills and long periods of repetitive motion (like filing papers, sorting items into bins, and handling small objects over and over again) should be avoided. I am able to perform some of these tasks, and am willing to participate if only a few such actions are required, as part of a larger activity.

I also have preferences for where I work and what types of jobs I perform. For example I do not care to work in a fast food restaurant wiping down tables using a rag and a spritzer bottle. However, I will use a rag and spritzer bottle if the activity is detailing a car or motorcycle.

My Bucket List: Activities and Goals

G Request: Self-Help and Work Related Skills

Mastering the rag and spritzer and garden hose (at home, at work, other places)

Getting myself a drink or snack at home

Communicating more spontaneously and effectively

G Request: Social Networking

Meeting and talking to new people when in a social group, or attending an event.

Making peer friends who are real friends. This includes different groups of people (disabled and able) who I can invite to my home, or meet out in the community.

These would be friends who share similar interests like music, or movies, or museums or hikes in nature, food, etc.

Making connections to the Mowat-Wilson community

G Request: Music in General, and Jazz Music, and History

Inviting friends over to play music together. Maybe, starting a band?

Taking a jazz history class (Gannet's request)...and other classes, or watching movies and documentaries of jazz performers (Thelonius, others), getting books on jazz, jazz poets, etc

Going to concerts and live performances around town

G Request: Read Newspaper or online articles and blogs, etc

To do more research into a topic I'm interested in. Or, just to learn new things. This means we can have a discussion about what we're reading, explore new words and ideas

G Request: Invite friends to social activities

Such as movies, galleries, performances, birthdays, events...

Disability

From “Unknown, Severely Handicapped” to Mowat-Wilson Syndrome

A Brief Gannet History - written by Amy Hosa, Gannet’s mother.



Gannet was born in 1981. Within the first 6 months, his diagnosis was explained as 1) “static encephalopathy” - disability from birth, and they thought there might have been “some kind of insult” very early on in gestation, and 2) “severely developmentally delayed, possibly blind” cause unknown. Gannet didn’t have the clinical diagnosis of Mowat-Wilson Syndrome until he was an adult. Mr. Mowat and Wilson published their finding in 1998. Gannet’s genetic specialist diagnosed him in 2005.

Medical journals are now publishing data by experts who are developing textbook definitions that describe the range of challenges, and the many variables and expected outcomes within the Mowat-Wilson population. Each Mowat-Wilson person is different, and human potential is not a scientific prediction. If you are a family member or professional, do all you can to forward your child’s progress, and be inventive and creative in developing an approach that is tailored to the child’s needs, not his or her diagnosis and expected outcome. In hindsight, raising a child with an “unknown” disability caused me a lot of anxiety – because Gannet’s progress was so divergent from milestones and norms – but the “unknowns” also allowed us, the flexibility to explore a wide variety of solutions and interventions, and not just focus on the “expected outcomes.”

This is a brief summary of how Gannet functioned, along with a few insights about intervention and educational solutions from age 0-23.

Pre-Mowat-Wilson Diagnosis for Gannet

While calling him the “puzzle baby” Gannet’s doctors and educators created a “functional diagnosis” that described his “severe/profound handicaps” by describing the variety of major and minor disabling conditions - neurological, intellectual and physical - and documented how they affected his ability to

function and develop. When it came to filling out forms, they wrote: **cerebral palsy, developmental delay, vision impaired, no speech.**

Similar Parallels in Deaf-Blind and Severe Autistic Populations

Based on this “functional diagnosis” and observation of how Gannet reacted to sensory input and how he developed socialization and skills (or not), he easily blended into the **deaf-blind and severe autistic populations**. Their functional challenges mirrored Gannet’s behavior and abilities. We collaborated on early intervention strategies with parents and developmental specialists of deaf-blind and autistic children. It didn’t matter that the clinical diagnosis did not match. The strategies and interventions for neuro-sensory development, developing social skills and communication for the deaf-blind and autistic community offered the best insights to the many sensory, therapeutic and educational approaches that were very beneficial to Gannet’s success.

The Medical Diagnosis

From a doctor’s report: Static encephalopathy, Hirschsprungs Disease resulting in a colostomy at 4 weeks old, hypospadias, agenesis of the corpus callosum, severe developmental delay, grand mal seizures, left focal (right brain origin) with left body Todds paralysis following (controlled by meds), frontal lobe seizures, non-verbal, legally blind (diminished vision and hearing of cortical origin), nystagmus and strabismus along with marked esotropia in right eye, cataracts in both eyes (lenses replaced), cerebral palsy, spastic hyper tonus in all four extremities, hyperactive DTRs in the LEs and normoactive in the UEs.

At Age 24: The diagnosis is Mowat- Wilson Syndrome

A new genetic anomaly was discovered in the early 2000s by Doctors Mowat and Wilson. Gannet was identified as having this syndrome. This did not change Gannet, or cause us to change the course of our instruction or interactions with him, it simply provided some interesting background regarding the cause of Gannet’s disability, and news that he was part of a tribe. What a trip!

What Is Mowat Wilson Syndrome (MWS)?



IN BRIEF: MWS is caused by a mutation or absence of a particular gene located on chromosome 2 termed ZFH1B (also known as SIP1), which produces a protein that regulates the action of other genes, many of which are involved in development. As of 2006, 99 individuals were reported in the literature to have

MWS, but experience with newly discovered syndromes suggests that it will be found to be more common.

Identifying features of Mowat-Wilson syndrome (MWS)

People with MWS often have moderate to severe intellectual disabilities, delayed or absent speech, seizures, and congenital heart disease. Motor milestones are always very delayed. In some cases, like Gannet's, people with MWS are missing part or all of the corpus callosum, the structure connecting the left and right hemispheres of the brain. Here is a link to a uTube video showing 3-D modeling of the corpus collosum. [Watch Video](#). Gannet is also among the approximately 60% of people with MWS who have Hirschsprung's disease, a neurological anomaly of the colon causing bowel obstruction and severe constipation, and was given a colostomy at 3 months. People with MWS also have characteristic facial features, including a prominent narrow chin, wide set eyes, and a broad nasal bridge.

Educational and therapeutic strategies for persons with MWS include the coordinated efforts of teams of medical and educational professionals including genetic counselors and orthopedics specialists; early infant intervention program specialists; physical, occupational and speech therapists; vision and orientation mobility specialists; special education teachers and resource specialists; among others.



The Mowat-Wilson Foundation offers the results of a study of 39 persons with MWS, on their website at [The MWS Study – Summary of Findings](#).

A Mowat-Wilson Study that Included Gannet

The study, titled “Clinical Features and Management Issues in Mowat-Wilson Syndrome,” was published in 2006. The authors not only describe the genetic anomaly, but also describe the effects of MWS on 12 patients in the United States – 9 boys and 3 girls. Gannet is “Patient 7” at age 23. The article covers the variety of effects of MWS on each individual, such as growth parameters, facial features, neurologic findings, behavior, seizures, neurological imaging, medical conditions, intervention strategies. It also includes a table on the developmental outcomes of the two oldest in the study – Gannet at 23, and “Patient 10” at 21 years. Dr. Blumberg and Kim Barr, two of the authors of the study, are part of Gannet's medical team in the Genetics Dept. at Kaiser.

How to cite this article: Adam MP, Schelley S, Gallagher R, Brady AN, Barr K, Blumberg B, Shieh JTC, Graham J, Slavotinek A, Martin M, Keppler-Noreuil K, Storm AL, Hudgins L. 2006. Clinical features and management issues in Mowat-Wilson syndrome. *Am J Med Genet Part A* 140A:2730-2741.

A History of Gannet's Development & Milestones



At age 0-3, Gannet's challenges included:

Attending an Easter Seals infant stimulation program 2 mornings a week, then a 4 morning a week program at age 2.

Floppy, could not support himself. He was extremely low functioning and missed milestones in all areas of development, had little response to stimuli. Progress to improve/change was extremely slow.

Asymmetrical - one side of body is weaker than the other. The therapy model was NDT (neuro-developmental training - stimulating pathways that were not being activated) for weight bearing and motor planning to make movements, and to get his motor planning more symmetrical

Does not learn by imitation. Teaching was hand-over-hand with tactile and voice cues.

We thought he was totally blind. He had no visual recognition of parents' face on sight (until age 4), but did respond to our voice (with glee) as recognition of who we where. Gannet is labeled legally blind. Brain wave tests indicate that the image is being transmitted to the visual cortex, but he has to learn how to use his vision functionally to have meaning. I am told to "teach your son to see." We spend years on visual training with motion and light boxes to help neurological connections to "rewire" for eye-hand coordination and object recognition. Also has no depth perception from strabismus.

Doesn't make eye contact, but uses peripheral vision fleetingly and looks towards windows and lights. Focus wanders, needs redirection. Minimal social behavior. The "Blind Babies Variety Club" (no kidding, their real name) was very helpful in visual stimulation strategies, and also referred us to Easter Seals to attend to Gannet's physical and motor deficiencies.

Very few vocalizations and babbling. No spoken language developing.

It's like each sensory area is a totally isolated experience. Goal is to build new neuro-pathways for coordinating sensory input, for quicker response time, and

hope that the neural-maturation process will continue beyond “normal milestone” normal age limits. (It did...sporadically)

Has little interest in developing fine motor skills, such as turning knobs, exploring toys or objects. Has a “primitive” palm and finger grip for small items, instead of using just fingers. Refuses to hold onto objects, will drop or fling items. The exception is his bottle, and drink cup, and spoon. Food is a great motivator for his healthy appetite!

Is tactile and orally defensive.

And the list goes on and on, but please note, he was a lovable little guy and was quite a trooper to put up with a hell of a lot of “infant stimulation program” hands-on intervention.

At age 5-8 – Gannet begins emerging out of his shell



Gannet finally took his first step in a walker and could stand vertical without support at age 8, began to make intentional communication by pointing to a few pictures more consistently, recognized his name, and was actively leading us places to communicate needs. He absolutely refused to point to “yes” and “no” icons, but we discovered he would “tactile sign” yes and no. He began to reveal his personality, intelligence, and a sense of humor. Gannet’s progress was painfully slow and continues to be, but things do keep changing! The only bad news was the colostomy reversal was unsuccessful, and he developed grand mal seizures (upon awakening from sleep) which are controlled by meds.

MRI imaging reveals absence of corpus callosum (the nerve fiber bundles that pass through and connect the entire left and half hemispheres of the brain). Perhaps that explains why it seems like G’s reaction to sensory input - to touch, sight, and sound stimulus - seemed scrambled or non-existent and he needed 10-20 seconds to process before responding.

At age 8-13 – A turning point in expectations, actions, abilities

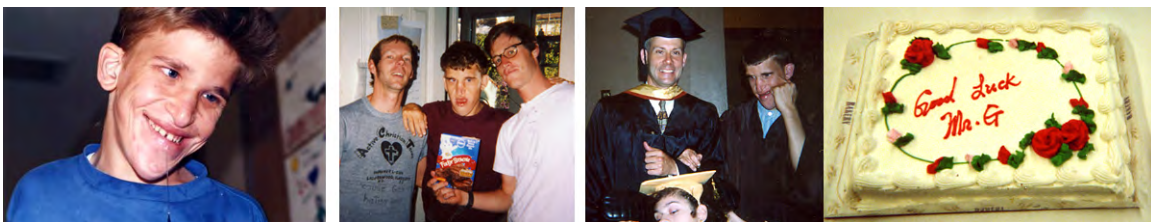


Mr. H, Gannet's elementary and middle school teacher ran a class best described as a cross between MTV and boot camp – he offered the most challenging, intense, amazing, stimulating, in-your-face yet respectful classroom strategy for the most severely handicapped and behaviorally challenged students in the school district. Nobody got to slide, and everybody had to raise the bar – staff, students and parents. He persevered to find cracks in his student's armor, made contact and evoked amazing responses. He was a radical professional and relentless - you either loved him or hated him. Gannet thrived in the excitement and intensity of this approach and began to emerge from behind his wall.

Gannet was expected to take full responsibility for his success or failure...and pay the consequences.

To our surprise, Mr.H also tested the parent's premise and beliefs, and would get in my face – “so why is Gannet whining when expected to do this? Still in diapers? Can't take off his coat? You're still pushing him around in a stroller? And, one the day at the carnival, “Mom, you do not need a ticket for the Tilt-a-Whirl, he's going on the ride by himself with his friends” (my knuckles were white, but at least I negotiated that G sit in the middle, between his 2 less floppy buddies. Gannet survived all the above, and his abilities grew in leaps and bounds - as he never wore a diaper again in his life, hung up his coat and bag, could walk 4 miles every Friday, do simple spelling and math tests. **Raising the bar for higher expectations, while learning to let go of Gannet and allowing him to take full responsibility for his success and failure was a new and important concept for us as a family to embrace.**

Age 14-22 – High School Years



Gannet was emotionally ready for high school, and really enjoyed the new scene and status. He had minimal options for integration (the lunchroom being one)

with the regular students, but between his classroom and the community, it was a good program. He still had a 1:1 aide, and received all the specialized services – vision, orientation mobility, speech, physical and occupational therapy – as well as classroom instruction and community training. A unique thing happened with the specialists, they began working together and cross-pollinating their services with each other’s expertise. It was a first, and they put together some really creative activities for intellectual, physical and sensory stimulation. Gannet’s vocabulary expanded, and he received his first real augmented communication device, which was too heavy to travel with him, so he continued to use his paper icon book in the community and at home. For his job training, a local motorcycle shop adopted him and set him up detailing its used motorcycle line. G could barely keep the rag and spritz bottle in his hand, but it was motorcycle heaven. Gannet had to negotiate a faster pace of life, with school hallways filled with action and drama. He learned to pick up the pace, and walk a straighter line. And like a typical teen, to hold his head up and ‘look cool’ when he wanted to impress certain students on the street or hall.

Advice from Mom: At this time I also started giving G a reality check about the adult world, primarily that *“the world is NOT your oyster, and I will not be there. The more skills you can build and the more you are willing to participate and cooperate with teachers and caregivers, the better your life will be. If you sit back and be a passenger, you will be treated like an invalid, stuck in a corner to suck on your hands and bang your head...life will be miserable. It’s your call Gannet.”*

At age 23 - Gannet moves into his own apartment, goes blind.



Gannet was so ready to move out in Supported Living, and he had a ready-made team of staff, some who had worked with him for years in high school and others who were their friends. This was a time of transition for Gannet, and I would say his development and skills went on a plateau. However, he was thriving with his new “family,” and was living the life of a hipster in SF’s Mission District and art scene. A documentary movie of his life, *The Key of G,* features the relationships between caregivers and Gannet at this time. Trailer and more info and photos are at <http://www.lateralfilms/keyofg>.

During this time, within a year, Gannet went blind in both eyes due to cataracts. This was devastating to him, and he became very angry, withdrawn and fearful. The surgeons were not going to replace the lenses if Gannet’s habit of banging his head, and hitting his eyes could not be curbed, and post op he would have to wear a helmet and protective eye goggles that he would not tolerate and rip off.

For another year we used braces and behavior modification along with straight talk, and at long last Gannet's proclivities abated enough, which proved that with arm braces he could not rip off the goggles or helmet during recovery. Surgery was successful and G's vision and personality bounced back. The helmet and glasses are history.

At age 24 on - Mowat Wilson Diagnosis and New Seizures

The Mowat-Wilson diagnosis didn't change a thing...except it was fascinating to know that **he belonged to a "tribe"** of similar people who looked like him, and shared characteristics.

Frequent frontal lobe seizures were diagnosed, and mostly controlled with meds.



In his 30's – Gannet is still adding skills and learning

Gannet continues to mature and develop new skills. It's amazing! Abilities – ones that I'd entirely wrote off by age 10, like taking himself to the toilet - actually became reality in his late 20's, as did many other skills like setting the table, getting food out of the fridge, making complex sentences and thoughts. Gannet has matured and can deal with doctors and appointments, and follow directions to be cooperative. He understands process when explained, and can be patient. I need to pay tribute to Alex Gallego, his primary staff and household coordinator, who has the patience to be Gannet's adult mentor, as well as a good friend who keeps raising the bar. At this time, Gannet has an incredibly good, productive life. He is asked to make choices, and has control over most aspects in his daily life, despite the fact that he still needs 1on1 facilitation for key parts of all self-help skills and daily activities, and requires 24/7 care for facilitation and safety.

The Key of G – a Documentary about Gannet

If you're interested in getting a glimpse of Gannet's life at 22-24.



THE KEY OF G is an award-winning feature documentary about disability, caregiving and interdependence. The film follows Gannet, a charismatic 22-year-old with physical and developmental disabilities, as he leaves his mother's home to share an apartment with a close-knit group of artists and musicians who support him, not only as paid caregivers, but also as friends. Together they create a uniquely successful model of supported living, and a compelling alternative to institutionalized care.

LINK to website: www.lateralfilms.com/keyofg

Medical Issues

General Health and Symptoms

I am in good health. I have a yearly check up with my medical doctor and neurologist, yearly lab tests, and routine eye exams for pressure.

DIAGNOSING PAIN, SICKNESS and IDENTIFYING SOURCE

For serious painful illnesses and injuries (like an ear infection or slipped kneecap), or bumps from bad falls, I almost never cry, and don't necessarily point to or grip the pained or hurt area. Rather I shake and moan (and people think I'm having a seizure). If it's an invisible pain or injury, it's only through careful observation and physical examination, along with using my iPad communication symbols and body page for me to explain, that one can figure out what is going on, and how severe it is. Diagnosing my symptoms can be confusing.

WHEN IN DOUBT – TAKE ACTION

If I am showing a symptom of pain or illness, consider that I need attention, and you need to take action now. My health insurance, Kaiser, has a medical advice line with an advice nurse. Call it ASAP. They can give you a home remedy, or make a drop-in appointment to see a doctor if needed – day or night and weekends, 24/7. Document all illnesses, injuries and any calls to doctors and prognosis. Alert your supervisor and my supported living coordinator of all the above. If you need to take me in to a doctor, also please call my mom to let her know what the prognosis is.

MEDICAL ADVICE & APPOINTMENTS: 415-833-2200 (open 24 hrs)

If a life-threatening medical emergency, call 911.

LINK: to listing of Gannet's doctors and contact info.

The Colostomy Bag



A detailed colostomy care guide is in video and print. This is just an overview.

I've had a colostomy bag since I was about 4 weeks old, so it's like a second skin. I do not pull it off, although it gets itchy and I scratch.

The bag gets EMPTIED when full of air, and/or if it is 1/4 full of bowel. The bag stays on for 1 to 4 days.

The bag gets changed, or REPLACED, at least every four days, or when it undermines (bowel begins to leak under the seal).

If colostomy supplies are running low, alert my coordinator to reorder. If unavailable, re-Orders of Colostomy supplies are made through Kaiser. Give Gannet's medical doctor a call with the request for that information.

Seizures, Side Effects and Medication



If I miss my meds, I will have seizures. With meds they are controlled. Document all seizures that you observe on paper, and alert my SL coordinator.

Grand Mal seizures are intense, and only happen upon awakening from a deep sleep. My whole body and face contorts and twitches and they can last for a few minutes. Lay me on my side, and protect me from injuring myself while they last. When they've stopped I experience a condition called **Todd's Paralysis**. The left side of my body is paralyzed (like a stroke victim) and I need to sleep it off for at least a few hours. Depakote is the medicine for this seizure.

Signs of **frontal lobe seizures** are when my eyes twitch rapidly, and I will just stop in my tracks, and slump from weakness. Immediately, stop what you're doing and immediately get to a place where I can sit down to rest awhile, until I recover. Topimax is the medicine for this seizure.

SEIZURE MEDICATION

Caregiver administers all medications, pills, ointments, etc. I take pills (one at a time) with water on a table spoon.

Depakote

(250mg tabs), total 2000mg/day for grand mal seizures.

AM: 3 depakote, Lunch: 2 depakote ; Bedtime: 3 depakote

Topimax

(25mg tabs), total 100mg/day for frontal lobe seizures.

AM: 2 Topimax; Bedtime 2 Topimax

Over the Counter Meds

No Meds containing Alcohol! If unsure, check with Kaiser to see what is compatible with my seizure meds. Some "bad" combos can knock me out. My medicine chest should be stocked with ibuprofen tablets, cough medicine +

expectorant, powder for my socks and underwear, fungal cream or spray for jock itch and athlete's foot, malox or anti-acid for barfy stomach, cold sore cream.

When recuperating from a high fever, or stomach virus with a very empty stomach give me lots of water and peppermint tea to drink. The first food is usually 1 or 2 peeled baked potatoes for the first few meals. If I gag at the sight, I'm not ready.

Doctors and Medical Contacts

Kaiser, San Francisco is Gannet's main health care provider

Alex Gallego has authorization for access to medical information and to take him for treatment

Medical contact information is on an addendum, as a separate doc for privacy.

Behavior

For behavior intervention techniques, see the Task Analysis section, “Behavior Modification Tactics”

Positive Social Behavior and Affection

PREFERENCES: I can communicate preferences for people I want to get together with, when I want to be social or when I want to chill. I enjoy seeing my friends. I like to do group activities. And, believe me, I have people that I don't care to be around as well, and hopefully you'll understand my signals.



THE TACTILE WORLD: I build relationships with people through touch and sound, more so than through eye contact. Touch is a key a building block in my world.

PERSONAL GREETINGS: I like to get and give a pat on the shoulder, or a hug as a greeting. Sometimes I have a mannerism, for lack of better words for you StarTrek fans, that is like the Vulcan mind meld. We touch foreheads and sustain the pose for a moment. Another greeting – a special one for favorite people – is the raspberry, where I spit in your face, smile and laugh. I'm repeatedly told that a raspberry is not socially acceptable, and should be discouraged.

HUGS and BACK SCRATCHES: Among family and close friends, I also give a great hug in the morning, to say goodnight, etc. I enjoy a firm, sustained hug from my family and friends, and will embrace them with both arms and pat them on the back to show my affection. At bedtime, I might fling your arm over my head to my back, as this is a request for a back scratch or back rub - for as long as you have time.

Negative and Anti-Social Reactions



TANTRUMS: During some activity transitions, and when frustrated or fatigued, I can throw a hissy fit with outbursts of frustration that exhibit as: face slapping, head banging, hand slapping, hand biting, shaking my body, and disturbed vocalizations. *Staff are advised to use the behavior program, it works. See the video.*

SLAPPING: I am usually not intentionally abusive to other people, just myself. However, I am known to occasionally slap strangers (old women and children) randomly when frustrated by something, or tired.

SENSITIVITY TO BABY'S CRYING – YOUNG CHILDREN WHINING

This will cause me to have a hissy fit, and can be averted with conversation, to rationalize that yes the baby is crying, but it's only talking, everything will be ok, just ignore it, etc...and breathe deep, 1, 2, 3... In general, I do not tolerate young children around me, especially ones running about. I might take a swipe at, or upset a baby stroller. Be alert.

Motivation and Learning Modality

To The Best of My Ability

Like most folks, I am proud of my work and doing chores. I like to participate in taking care of myself and try to make decisions about my life. I like to go to sleep when I want or stay out late and be active. When I really want something, or wants to impress somebody, I can be totally cool, competent and independent. However there are also times when I'm non-cooperative or like a little TLC, and prefer that people wait on me hand and foot. Everyday life is likely to be a mix of both extremes.

For me to do something "to the best of my ability" requires that staff and friends be facilitators, and have patience, because I need to do things at my own speed.

This means that:

- 1) I take a longer time to process my thoughts, and what you say to me.
- 2) I need time to motor plan (to figure out how I should move)
- 3) I need time to sequence (what to do next), and sometimes need cues.

Staff and friends should be aware NOT to fall into the rut of "taking over and doing it for me" because it's faster, easier, and you think that makes me happy. I prefer to be my own person, and do things at my own pace with the least amount of assistance. I become angry when people control my life, and just lead me around.

Examples of My Capabilities and Levels of Assistance Needed:



Totally Independent Examples: I can be independent like turning on my keyboard and entertaining myself for an hour, then getting up and walking to the bedroom and climbing into bed and going to sleep. I might not have my PJs on, but I've taken care of my needs. (You'll have to help me into my PJs) upon awakening I can get out of bed (and with just a few minor prompts) I can walk to the bathroom, pee, maybe even get myself a glass of water, then walk down to the kitchen and pull a drink carton out of the fridge for my breakfast, and carry my cereal bowl to the table. Expect me to walk up and down the stairs, carry the grocery basket, or choose my path through a museum to find what interests me.



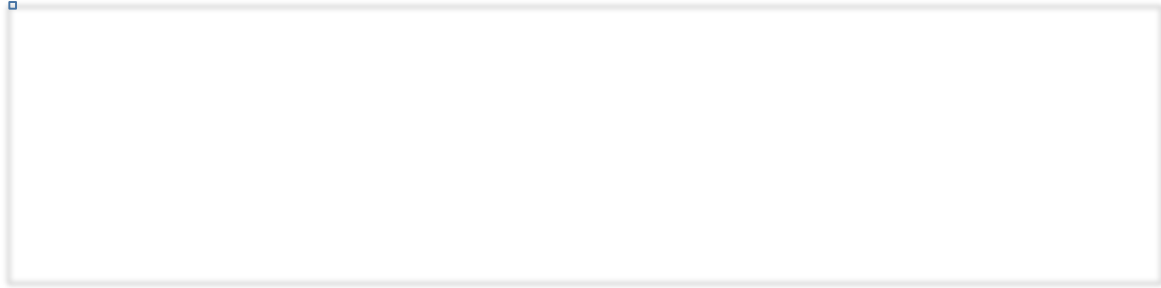
Independent AFTER an initial prompt: Examples: Some days I just walk into the kitchen before mealtime, and stand there doing nothing. I need a prompt, like a point or tap, or a verbal direction to cue me to what I need to do next for my chore or task. Some days, it might take a light touch on an elbow for me to reach out and say hello to a friend, or a finger point and a tap on the table to get me to put my glass down. I usually respond to the cue and will follow-through.



Semi-Independent, needing prompts and/or assistance: Examples: On some days picking up my bowl and setting it on the table requires a mix of verbal prompting, animated finger points, even a touch on the elbow at each step to help me sequence and stay focused. Likewise recycling hangers and sponging off the car need some hand-over-hand help for me to hold on and get the task done. To do my laps when swimming, I use “noodle” floats to swim along with verbal encouragement (and a little tickle on my feet) to keep me kicking. I can do my water-walking and knee bends independently.



Totally Dependent on You: For example, I wait for you to get out my communication device. Some days I need your help to focus my attention to point to and say the icon names to facilitate the conversation. I do not cook, take a shower or brush teeth myself. Those tasks are either accomplished by staff 100%, or shared by giving me hand-over-hand assistance on parts I can participate in.



WATCH THE VIDEOS

The task analysis “How-To” videos and printed documents offer specific examples of how you and Gannet interact during activities, and showcase his level of abilities. The videos and documents are on a share point site, with permission to access limited to individuals working with him, or by special request.

Learning Modality — Gannet’s World — Overview

Skill Acquisition and Accomplishing Tasks

Skill acquisition is measured in small units and success comes after years of repetition and trying. Don’t give up if I don’t “get it”. Have blind faith that your verbal and physical instruction is getting through, and will eventually succeed.



A Multi-Sensory Approach

I perceive the world through different filters. It takes a while for new caregivers and instructors to fully understand and appreciate this basic premise of “Gannet’s World”.

My perception of the world is formed by a brain that interprets and routes sensory information in a very different way than “normal.” When introducing a new task or learning regimen, you need to appeal to as many levels of my intellectual and sensory awareness that you can (speech, sounds, touch, vision, and neuro-muscular input. Some “regular” therapists even paid attention to my auras and chakras - whatever works!) My brain is wired WAY different, and it literally TAKES LONGER TO PROCESS a response to stimulus.

Here's a brief background of my sensory challenges today

VISION

Note: I see fairly well, yet I am considered vision impaired, because the impairment has mainly to do with sensory input, or how my brain is processing and connecting the visual information. Also, my eyes don't always work together, one is off kilter. If I'm interested in a page or picture, I like to look at it close-up to study it. I don't sustain eye contact, but that does not mean I'm not paying attention if I'm looking away. I use my vision discretely - with a side-glance or occasional eye contact at the critical moment. I see quite well, but frequently need a reminder to "LOOK" at the critical moment to focus when doing something. Once focused, I can read words and icons, and point to words and icons to communicate, I can find things I need, I can navigate familiar routes, and can maneuver well in space.

HEARING

My most acute sense is hearing. I explore and understand the world through sounds. Note, that while I don't necessarily use my fingers to explore through touch alone, I prefer to sample and know places and objects by hearing the SOUNDS made by touching or tapping on them in different ways. If you want my attention, or me to focus, it helps if you say "LOOK" and then make a sound by tapping to help me focus where you want my attention.

TOUCH & MOVEMENT

I learn how to do things through your touch (physical prompts) and movement; or by your physical hand-over-hand modeling (someone moving my hands or body through the motion required) while they talk to me, explaining the details of the expected outcome. I also require your touch/presence for "facilitated communication" (explained elsewhere). I like to make physical contact to express emotions. I don't like to hold random things in my hands, nor feel furry things. I cannot stand anything on my face or head.

SPEECH

I don't speak words, except for "achoo", "buh" and "mumum", but I understand what you say (receptive language). For expressive language I point to picture icons - symbols and words on an iPad with a digital voice. I will also read and point to hand-written words that you write on a tablet, or I will lead you somewhere. Pay attention to my vocalizations and gestures and their context, as they also have meaning.

COORDINATION

There are times when I need help to get my senses aligned to work together. You might literally have to guide me to "look" at something, reach out and "feel"

something, and “listen” for cues. You also might have to remind me about motor planning, to sequence me through an action.

IMITATION

I do not learn by observing and imitating.

Rather, you need to explain the activity, and TALK me through what you’re trying to get me to do while HAND-OVER-HAND facilitating me through the motions. Don’t forget to TELL ME WHY I’m doing something, because I do not like to perform, and am more cooperative when we’re doing something for a reason that is real and functional in the moment.

GENERALIZATION

Even though I have a skill in one area, I do not necessarily generalize that “action” to accomplish a skill in another. For example twisting my wrist to open a door and twisting my wrist to pour a glass of juice exist in separate universes.

EXAMPLE of TEACHING TECHNIQUES and LEARNING MODALITY



Example: Teaching Gannet to Pour a Drink by *Listening to Learn to Pour*
Written by Mom and Chris:

In the bathroom, Gannet could already turn on the water, get himself a drink, then empty out the cup by twisting his wrist to pour any water left into the sink before depositing his glass on the counter. However, teaching him to pour juice into his cup from a little bottle at the dinner table (by twisting his wrist to empty the pitcher), was a complete failure - for MANY MANY years we tried. We’d model the process, and then do hand-over-hand facilitation. We’d tap the table to focus his attention; point with our finger to guide his attention to look at the “juice bottle” and “cup”. The result: he’d lift the juice container into the air and put it down, then pick up the empty glass, try to drink and swallow air. Try again. This time, hand-over-hand, we’d turn his wrist and say, “twist your wrist” to pour the juice. We’d tap his glass; guide his arm, say, “look”. Same result. Finally, years later, we tried a new approach: Chris said “LISTEN to the sound the juice makes when we pour it in your glass. You need to make this SOUND.” G was interested in the sound. It clicked. He now pours his own juice (not always 100% in the

glass) but he twists his wrist and pours while listening. G is a complex challenge, and we all have to be creative and patient.

Success in Learning takes a LONG Time and Patience

My processing and motivation to learn to do something can ferment for a very long time. I have mixed competencies and mixed physical challenges that take a long time to coordinate. Note that some days I function better than others. Please don't give up. I am still adding skills and competencies to my repertoire, and it just takes time and repetition, and your trust and belief in me that someday I will succeed.

TEACHING TIPS

OFFER PROMPTS, GESTURES, HINTS...and other helpful cues: I respond to a variety of prompts, gestures and cues. These can be spoken phrases, a light touch on an arm or elbow, a tap on a wall or object, a moving point to focus my attention, etc. How to use a variety of "prompts" is explained in the task analysis section.

AN ANIMATED DELIVERY and DIRECT APPROACH: When in school, I responded best to teachers who had a direct, animated manner in working with me. These teachers also told others to, "talk to me constantly", and explain everything. These were educators who raised the bar, challenged me to do better, to do more...and I did! I have a disregard for teachers who have a timid, quiet approach, and are willing to accept the status quo.

A few reasons why Gannet takes a long time to succeed:

Gannet does not learn through imitation or modeling. Teaching a new skill requires hand-over-hand and verbal prompts, breaking down skills into their smallest components to be learned bit by bit, and slowly linked together to complete the entire task.

Gannet is very slow to accept "fine motor tasks". With the exception of eating with utensils and routine activities (to carry and place objects, hold his car, toothbrush, etc), he will throw most items placed into his hands. He doesn't care to explore or manipulate objects, except if they make a sound. He can be successful, needs encouragement & creativity.

Gannet does not always generalize skills. If he learns a skill in one setting, he still might not be able to use that same skill in a different task. Skills for each task have to be learned in context.

Gannet's and Your Safety



Gannet's Stability – For His and YOUR Safety

I navigate all over town – stairs, busy streets, escalators and hills. Being safe, does not mean I sit at home. It means we work together, paying the proper amount of attention to how we navigate as a team. Here are 2 tips:

BEFORE YOU EXPECT ME TO MOVE 1) tell me what you expect me to do and 2) check that I am in the right position BEFORE I take off to stand up, get up from the bed or floor, out of the tub, step off a curb or into a bus, etc. I am able to do most things with very little assistance, if I am prepared and in the right position.

I Like to Feel Secure – I Hate to Fall

I have mild cerebral palsy that gives me a lopsided walk, and also limits my ability to use my arms to catch myself when falling. Take note: if I fall, I go straight down flat-face - hard on ground. My motor planning is slow, and I can't respond fast enough to catch myself. The good news is, most of the time I am quite stable because I am overly cautious, because I have a fear of falling.

I walk slowly. Encourage me to navigate independently when outside on sidewalks and flat areas when we have the time. Please tell me of any bumps in the sidewalk, curbs, steps, etc, so I can prepare for them. For stability when we need to walk at a faster pace, I need to hold onto you – preferably your shoulder or arm, or your hand. You should not allow me to lean on you, or bear my weight, as this will make YOU unstable, and create an unsafe situation for both of us.

I am not fragile, nor as uncoordinated as you might assume. Many staff are tempted to hold onto me tightly and guide me around, as if I'm incapable and might topple at any moment, or they try to pull me up the stairs or out of a car. I do not need you to be my crutch, or for you to be my hydraulic lift. You will hurt yourself. Use your brain, not your muscle...and I'll do the work.

If I am in the proper position, I can actually maneuver and do things for myself...like getting in a car or standing up. If I'm lagging behind, or being lazy, or leaning on you, please talk to me. I understand you and will comply. You'll be

amazed at all that I can do safely and securely with only a tiny bit of support, and how easy it makes your job!

Personal Safety and Lack of Problem Solving Skills

NEVER LEAVE ME ALONE: The staff must be aware of the environment at all times. You don't have to be on top of me, but always know where I am, and what I'm doing, and within hearing range. Never leave me alone, whether inside a house, outside, or in a car...never alone.

AWARENESS OF DANGER: I am very aware of many things that are dangerous or make me feel insecure, and will try to avoid them, such as: uneven floor surfaces and shadows, hot surfaces and flame on a stove, falling, etc. However, I might not notice a danger, or precarious object.

PROBLEM SOLVING SKILLS: If I find myself in a predicament, my ability to get out of trouble and problem solve is really poor. For example: I have bumped the cold water off in the shower. How did I react? I stood there and moaned under the stream of hot water. I did not even move out of the water's flow, nor did I turn the water off even though the faucet knob was in reach. If I fall, I can't motor plan fast enough, and fall on my face. If I am sidetracked (like a motorcycle engine goes by while I'm walking), I might trip or fall over a curb.

WANDERING AWAY: If the door is open or closed and unlocked, I can escape, negotiate stairs like a pro and end up exploring parked cars on the street in no time flat. I have also fallen down the stairs, wandered away in stores, escaped into parking lots, etc...

EVACUATION and ESCAPE PLANS: Although I can independently escape for my own pleasure, I cannot follow an evacuation plan. I will need complete assistance in an emergency to get to safety. In case of a natural disaster, like an earthquake, staff are required by law to stay with me and assist.

DEFENDING MYSELF: I am not traffic-wise, street-wise, people-wise or danger-wise. I cannot move quickly, or defend myself from a person, animal, vehicle, or unstable objects.

INJURIES and PAIN: Be aware that I do not cry easily, almost never, even in the case of a major injury that hurts like hell. Rather, I look stunned or groan. Please take action to find out if something is wrong with me.

These are my symptoms of pain (alone or in any combination): silence, moaning, shaking (you might think I'm having a seizure), a wide-eyed dazed look (like shock or being stunned). *Steps for assessing my pain, see "Medical Info" section.*

If you have any doubt, and suspect something – even if you're not sure - call medical advice, make an "urgent appointment," take me to the doctor.

Medical Advice at Kaiser: 415-833-2200 ; Call 911 for medical emergency.

A Thank You, from Gannet's Mom



Gannet began life as the limp “puzzle baby,” and most of the doctors offered little hope for him to achieve developmental milestones. As parents we were lucky to be referred to experts who gave Gannet the benefit of the doubt and allowed us to believe that he had potential to grow. His teachers, and therapists never set limits. We all worked non-stop as a team to stimulate and expand his abilities and worldview. Even now as an adult, through facilitation and mentoring Gannet is still learning how to see, still learning to integrate his senses into meaningful experiences, still learning to gain practical living skills. Of course we take plenty of time to goof off and have fun too.

The teaching never stops and the learning never ends. We deeply appreciate you reading this person centered plan, all your efforts and care in supporting a real and meaningful life for Gannet, for expanding his horizons to the fullest.

Thank You and Best Regards...

Gannet's Mom, Amy Hosa