PROVIDING SUPPORT TO PERSONS WHO ARE FUNCTIONALLY DEPENDENT AND EMOTIONALLY FRAGILE.

PART I: .... THEMES of "FUNCTIONAL DEPENDENCE"

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THEMES OF FUNCTIONAL DEPENDENCE

The happy themes:	The sad themes:
"I can do things if I see someone else doing it first."	"I can't do things till it becomes my own idea."
"I can do things if it's what I expected."	"Things have to be just the way I thought it was going to be" (or it blows my mind.)
"If you focus me I know what to do. When I know your expectations I can follow them. I can do things when I am ready and sure."	"If you don't prepare me I can't meet expectations. If I am uncertain I can't figure out how to begin to begin."
"I can do things if it's part of my familiar routine."	"I can't do things if I don't know how they will turn out."
"When I am involved in what I do well there are no problems."	"I don't know what to do when I don't know what to do. I 'act out' when I'm not occupied."
"When you are watching me I can regulate my emotions. If you watch me I can use self-control."	"When I am alone my emotions are out of control and I panic. Without your "eyes" on me I have no impulse control."
"If you give me rules I can use self-control and act like I have a conscience."	"Without your rules I act like I have no conscience."
"If you set my beginning and end points, I can do the middle part all by myself."	"I can't be "smart" without you telling me exactly what to do next." "If you don't do this for me I become megalomaniacal and have to control everything."
"When someone is with me I feel safe and secure."	"When I am by myself I am symptomatic."

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VALUES ISSUES IN PROVIDING SUPPORT TO PERSONS WHO ARE FUNCTIONALLY DEPENDENT AND EMOTIONALLY FRAGILE

The meaning of "dependently-independent":
The need to provide pro-active support:
How much support is "just the right amount?”
How to ensure a person being supported is not being over-controlled:

For those persons who are "functionally dependent", this characteristic exists to varying degrees. Some people are functionally dependent in only a few areas, some in a great many areas.

The attached pages are an attempt by this writer to provide a "voice" for those persons who, to be able to function in a relatively independent manner, require a protected, limited and rigorously guided environment. When intense support is provided, the persons described are able to live in a relatively competent manner that may be described as "dependently-independent".

The meaning of "dependently-independent": Parents and caregivers who well know the persons they are supporting who are “functionally dependent” are sometimes seen as being over-protective, as "spoiling" them, or of allowing themselves to be "manipulated". This may be the perception of any "outside" person who sees how well the person can do some of the time or under special circumstances, but is not aware of how impaired the person may be in areas where they are truly, functionally dependent.

The described levels of support, which are absolutely required in areas where the person is functionally dependent, could be perceived by an unaware "outsider" as being overly intrusive in the lives of affected persons. However, for persons who are very impaired in this manner, they cannot function without the levels of support described. The persons described go into recurring crises when these intense levels of support are not provided.

It may take a lot of time and resources to adequately support an individual who consistently demonstrates that there are areas where they are functionally dependent on others to be able to cope. These individuals require intense expenditures of time and resources anyway, every time they go into their repeated crises.

The need to provide pro-active support: Failing to provide pro-active support (where required) often results the appearance of severely challenging behaviors. These extreme behaviors are a reflection of the supported person's inability to independently cope with situations. With recognition of the supported person's areas of "functional dependence" structured guidance can be provided to assist them to cope. Failing to provide the required level of support on a pro-active basis may lead to the breakdown of community, educational and vocational placements, hospitalization, and/or the involvement of the individual with the Justice system. "Putting them back together" and rebuilding a support system is often extremely difficult to do.

> The idea is to recognize that, with persons who display functional dependence, ongoing support is required to prevent the predictable crisis from occurring. Acting pro-actively, in the long run, is a much better approach than trying to hold back the flood after the dam has already burst.

No one is immune from life's circumstances where we may become temporarily overwhelmed and require additional support and services from our community. There are a number of persons with developmental disabilities who typically require a pro-active increase in support every time there is any potential for crisis or conflict.

There are a number of persons with developmental disabilities who may require an increased level of preventative support throughout significant portions of their life span. Some may require extreme support all of the time.

How much support is "just the right amount?" Empowering people with disabilities is the ultimate goal. The method is to support individuals with their personal vision to be as independent as they can be, <u>and still be able to successfully cope with their world.</u>

> Sometimes the appropriate method is to provide people with a variety of choices and options and support them in their decision, whatever it may be. For some people, choices may be beyond their ability and having too many options may evoke anxiety, panic, and mental health crises.
>
> Sometimes the appropriate method must be to provide people with restricted choices and limited options, increased structure and supervision.

Which method is relevant to the individual depends upon the nature of the individual's personal vision, as well as nature of the individual's functional disabilities. (Examples: A mother who is developmentally disabled who may be able to adequately look after her child with someone "looking over her shoulder". A man who can "live on his own" if he receives a phone call every morning to assist him to organize his day and remember what needs to be done. A boy who lives with autism who can "independently" work in a natural environment if <u>everything</u> is perfectly set up for him in advance.)

How to ensure a supported person is not being over-controlled: Empowering people with disabilities is the ultimate goal. Sometimes, the only way this can be achieved is by structuring their life with certain restrictions to allow the person to be "dependently-independent".

Some individuals who require such intense support may not be aware of their need. The most difficult situation is to provide support to a person who requires medications or assistance in a structured residential, school or work setting who is not accepting of the assistance offered. In order to allow them to cope and function without going into repeated crises, some persons require a degree of unwanted intrusion by support services. For some it can be determined that providing such structure and assistance allows certain individuals to be successful and is empowering to them.

It is suggested that certain steps be followed to ensure that the concept of being functionally dependent is not used to "justify" attempts to over-control individuals who do not require this level of intense support. It is suggested that implementing the suggestions included here only follow after a team decision by a network of concerned persons who know the individual well. Let there be an informed consensus that the health, safety, and/or mental health of the individual requires the intense supports described and specify the areas where required.

Once a team decision is made, write these in very specific terms for individuals who require this type of approach.

- Include timelines for review and evaluation.
- Identify areas where it is crucial for care providers to never deviate from the prescribed, restricted approaches.
- Clarify the areas where the individual is able to cope with choices and options.

Continue to support the person to be as independent as they can be. But, do not hold back from imposing appropriate external guidance and control where experience has shown that it is in the individual's best interest that this is done for them.

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End part one of three.

GUIDELINES FOR CAREGIVERS

SUPPORTING A PERSON WHO IS FUNCTIONALLY DEPENDENT AND EMOTIONALLY FRAGILE

I. The meaning of "functional dependence":

Some persons with developmental handicaps have a great deal of skill under certain circumstances, but are extremely functionally disabled by their inability to <u>self-orient or organize their own behavior</u>.

There are several psychological factors involved: they may lack a sense of their own ability to affect others. (They don't understand that they can ask for help.) They may lack a sense of how cause and effect are related. (When something goes wrong they didn't mean to be "bad". "It just seemed like such a good idea at the time."); they may be unable tell apart the important from the irrelevant aspects of a problem situation. (They don't have any idea where to start. Everything goes over their head.)

Often the result of these factors is a lack of any sense of continuity between their experiences. Without a sense of continuity or where one "fits" in the social or "big picture", it is difficult to learn from experience, or to generalize learning which takes place in one circumstance to other, similar situations. (They don't learn from their mistakes.) Persons who are able to perceive situations only from their own, immediate-instantaneous point of view may endlessly repeat inadequate and maladaptive actions.

An inability to organize one's own behavior could be due to a number of cognitive-emotional factors such as extreme distractibility, severe attention deficit, severe deficit in immediate memory span, extreme anxiety, psychological dissociation, etc. These functional features may be seen in individuals with a wide variety of diagnoses, such as: autism, fetal alcohol syndrome/fetal alcohol effect, cerebral palsy, arrested hydrocephaly, severe depression, extreme mental health crisis, dementia, etc.

Features of "functional dependence" may be seen in any "normal" child who is developmentally, very young. Older children and adults who are still functioning at a very young developmental level may remain dependent on others to keep them organized and focused, similar to the level of support that would be provided to a young child.

The difficulty is with people who, in some areas, are obviously functioning at a much higher developmental level. They appear to be highly capable in certain areas, yet consistently encounter situations where they are equally obviously either incapable or dependent on others to be able to cope.

Some common factors in such persons are that they display fragile emotional states. They seem to be "smarter than they can act". They are <u>able</u> but cannot <u>self</u>-initiate.

They cannot sequence their own actions. These individuals are "functionally dependent" on their caregivers.

II. How to respond to dependent persons who are variable in their need for prompting.

Sometimes individuals display extreme variability in how well and when they are able to self-orient. When they are able to focus within a familiar context or on the basis of modelling, they may need no additional "scripting" or structure. This can be highly variable. One day a person may be able to independently do something well, and the next day require explicit prompting to be able to initiate the same action. **Accept the independent moments as a "gift".**

> Sometimes individuals have areas where their cognitive functioning is relatively intact and unimpaired by their developmental disability. People may display consistent and independent ability in these areas of relative strength. The difficulty is that having areas of strength tends to mask co-existing areas of true impairment and disability. This can lead both the supported individual and their caregivers to have expectations that are beyond the person's independent ability to achieve.

Be cautious about expecting that a skill or interactions that your supported person is able to independently do some of the time, is available to them all of the time. Sometimes individuals may become momentarily unable to orient. This could be due to some change in staffing or routine; being required to utilize some area of cognitive impairment; physical illness, or anxiety from a variety of other, internal sources. When such momentary disorientation occurs in a person who is functionally dependent they may become instantly, extremely disabled, and require support as a totally dependent person. Their area of disability becomes predominant, and they function at their own "lowest common denominator."

Whenever individuals indicate that they are having difficulty in self-orienting, be prepared to step in and be their "bridge" to successful functioning.

A. Avoid failure by supporting "perfect" performance. (The Olympic Gold metaphor.)

The "motto" is to give as little assistance as possible, but as much as necessary to ensure that the supported person is able to be successful.

It is a "set up" for failure to expect persons that are developmentally disabled to "do it for themselves", all of the time, before they have become taught explicitly how to be skilled at "doing it for themselves". For many individuals, this requires an understanding caregiver to cue them to do whatever they want to accomplish to an "Olympic Gold" standard. It is a "set up" for failure to expect persons who are unable to self-sequence their own actions to be able to plan how to reach their own goals. They need an intervening "interpreter" who can look at what they might be capable of doing. They need an understanding "translator" of their goals, who can assist the individual to be who they are trying to be in the world.

* Even a person as accomplished as Rick Hansen (the athlete who went around the world in a wheelchair) had to first have someone imagine how he could recover from the injuries he received when he was initially paralysed. He then had to be passively "drilled" through the motions until he had enough "muscular repertoire" that he was able to actively participate. To be able to do what he wanted to do (go around the world), he still required someone to "support" him with a wheelchair, provide access ramps, and a team to follow him, massage him, and prepare meals for him. He was "dependently independent". This is a relevant image and model for initially <u>over-supporting</u>, and being <u>intrusive</u> in the early stages of fostering independence with supported persons who have developmental disabilities.

B. Avoid failure by believing client is doing the best they can to cope.

It is equally a "set up" for failure to expect a person who is functionally dependent when they become disoriented to "independently" exercise self-control. For many individuals, once they lose control they require a knowledgeable caregiver to "reconstruct" their world for them. It is necessary to "rewind their tape" and to assist them to get back on a familiar track. When a person who is functionally dependent demonstrates "acting out" it is usually not a "behavior problem". It is usually a loss of focus and finding themselves immersed in an area of disability. They need to be rescued!

> The danger in taking a "behavioural consequences approach" at such moments is that this tends to "trigger" an escalating, defensive reaction in persons who are desperately trying to be successful and to follow expectations.

III. How to evoke the potential that individuals may, with assistance be able to reach.

This section is a caregiver orientation for how to provide certain, explicit boundaries to persons who are functionally dependent and emotionally fragile. How to be a therapeutic "coach-supervisor-facilitator":

A. Provide the supported individual with <u>certain</u> expectations.

For those who are not able to see connections or organize their own actions in a meaningful manner, it always helps to "solve the problem of life" for them. To assist a person to orient on what is essential, it helps to be direct, unambiguous and certain when providing externally organized expectations.

When the supported person is having difficulty in self-orienting, before each and every interaction, pre-define your exact expectations for how it will go between you this individual. Have a plan in your own mind for exactly how the supported person might behave, what the expectations are, and that you expect that the individual will perform to an Olympic Gold standard of perfection. (This may relate to social behavior at a shopping mall, physical participation during toileting tasks, how the supported person will go to sleep at night, etc.)

Have a pre-arranged "Olympic Gold standard" for each area where the supported individual displays a need for guidance to be able to adequately function.

B. The difference between being angry and being explicit.

One doesn't have to be emotionally "angry", "mean", "firm", or "bitchy" in order to be objectively clear, certain, explicit, emphatic, direct, persistent, and insistent. It is caregiver certainty about exactly what is required for the supported individual to be able to accomplish their goals that "works".

C. You pull the strings. They do the work.

Imagine that the person who is "functionally dependent" is like a "puppet" {remember Pinocchio?} that is sitting on the shelf with all their "strings" dangling. They have to sit on the shelf until someone comes along and "pulls their strings" (tells them explicitly what to do, movement by movement). Then they are perfectly capable of doing most of what they are told to do. Their disability is that, on their own initiative, they are unable to animate themselves.

Telling such a person who is "functionally dependent" exactly what to do "works". (This must be done in language suited to their level of comprehension.) This approach leads to a well-managed, dependent person who is able to function as directed. However, being functionally dependent may also lead to resistance from individuals who are "smarter than they can be." That is, persons who are able to form their own intent but are unable to accomplish their intent without assistance.

D. You fail to pull the strings; they are abandoned, angry, jealous and helpless.

Without external direction, a person who is functionally dependent in this manner is left in a "void". When their "strings" are not being pulled by an external source, a person who is alert, aware and eager to engage (but unable without external prompting) may experience anger at being abandoned, extreme anxiety or other psychiatric symptoms. They may act very jealous when they see the direction which they require being given to others and not, at that precise moment, being given to themselves.

When a person who is functionally dependent is not receiving external direction from a caregiver, this may also lead to varying degrees of "acting out" behavior. They may develop a repetitive repertoire of things that they do, when they are not being told what else to do. They may display a repertoire of highly ritualistic and disruptive behaviors to "bridge the gap", or "fill in the void."

E. Use just the right amount of external "pull". How to tell which strings to pull.

The challenge when providing intrusive, external guidance and structure is to determine just the right amount to evoke the spontaneous and "natural" participation of the supported person without super-imposing too much on them. The goal is to evoke their spontaneous potential to meaningfully participate in the world around them.

All individuals give "hints and clues" about how they will best accommodate to external direction. Imagine that the "Pinocchio puppet" has a "potentially independent person" inside. Ask yourself, "Who would this person be if they could 'pull their own strings'?" This is revealed by their positive response when external direction is provided. Their eager and helpful participation, active enjoyment and engaging when externally directed, or their motivated over-focus on some small aspect of their repertoire may show this. Once you recognize the intent of the supported person to be in the world, your task is to become their "maestro".

F. Direct supported person to be who they are <u>trying</u> to be.
Insist on, and support "perfect" performance.

Become a "puppet master" {remember Gepetto?}, whose goal is to pull all the strings (give all the cues) for the supported person to be able to accomplish what their own goals may be, <u>if they could</u> put them into action for themselves. Be creative in dictating their task and social scripts for them (with them if possible), and then direct them to pull all the strings (follow all the step-by-step-cues) that are required. Have them rehearse and memorize these scripts.

Once these scripts have been provided and <u>over-learned</u>, the final direction would be to tell the supported person, "Now pull all your own strings". Through this procedure you "dependently" create the ability of the individual to be "independent under direction," or "dependently-independent." Such direction "releases" the individual to be the "potentially independent person" who could only be "released" by first being "imagined", and then rehearsed by an understanding caregiver. Under these circumstances many persons may then <u>spontaneously</u> be able to be "dependently independent". Following these memorized scripts can become their ritual, or the thing they do when they don't know what else to do!

> Unless this is first "imagined" for them by their "puppet maestro" caregiver, a "dependent" person will not be able to become "dependently-independent". The "Gold standard" of step-by-step actions required to be successful will provide you and the supported person with a "script", and will define which "puppet strings" the individual will eventually be expected to "pull" for themselves.

IV. Interpersonal role-relationships that "work":

A. How to respond to dependent persons who function like "emotional radar".

Some individuals who display fragile emotional states appear to take their own stability from the stability and certainty of whoever is in their immediate surroundings. They seem to function like "emotional radar", reflecting the emotional certainty of their caregiver, in the moment. This places quite a large responsibility on a caregiver to always be confident and certain.

Individuals who "take their identity" from their environment tend to reflect and react to either the positive or negative emotional mood of the caregiver that is in their immediate environment.

> In one of his workshops, David Hingsburger commented "Your frustration due to your caring, looks like anger to your client. Be aware."

Use positive suggestion. Rehearse with the supported person exactly what is expected for them to be successful. Give positive suggestions to the individual about how confident you are that he/she will be able to respond well and be successful. To allow the individual to have feelings of confidence in themselves, first project your own confidence in their ability so that this is available for them to "reflect". To get the best from the supported person, believe that they are able to do their best performance with you!

> For some persons, rather than by affecting their sense of pride and confidence, this "works" on a more immediate-sensory level. It is less about ability to perform, than it is about ability to reorient-in-the-immediate-moment. For example: A person who is unable to orient towards doing self care might "independently" decide to take a shower in response to caregiver expressing enthusiasm about "how good it will feel to have hot water on you". In this case, to get the best from the individual, believe and project your belief that they will enjoy the experience!

Any uncertainty in caregivers about what is going to happen if the supported individual begins to become over-aroused tends to be "picked up" by them. This may cause them to feel insecure, uncertain, and may lead to an increase in their level of anxiety and arousal.

Any sense of personal vulnerability in caregivers who "take it personally" when working with difficult individuals; or caregivers who are intent on "teaching who is the boss" tends to be "picked up" by the person who functions like emotional radar. Any interactions, which are initiated on this emotional base, can immediately escalate into a power struggle.

Any emotional distress a caregiver is experiencing from their own, personal issues may be "picked up" by sensitive individuals and perceived as emotional rejection directed towards them.

It is necessary for the caregiver who is working with such persons to <u>project</u> "I like you", "I'm glad to see you", "I accept you for who you are". One way to do this is for caregiver to "charge up" themselves with one of their <u>own</u> happy memories so that they have a smile on their face before coming into the presence of such a reflecting/reacting individual.

B. The meaning of using "following guidance" with persons who are emotionally fragile.

There is a certain "self-perception" each caregiver needs to have to successfully provide "following guidance" to persons who function like "emotional radar". ("Following guidance," means to take your lead from the actions of the supported person, then to give them the type of guidance they require to facilitate their acceptance of cueing from caregiver.)

> Imagine yourself as the person who knows with a degree of certainty, where the interaction between you and the supported individual is going and how it will unfold. Ensure you have developed comfort and confidence in your care giving role. As the caregiver, it is you who are responsible for positively constructing the dependent person's environment and social interactions. Do this in a manner that will assure the supported person the greatest likelihood for successful participation.
>
> Pay attention to your own emotions and level of confidence. You should be working towards exuding your own confidence and emotional stability so that the supported person is able to feel safe and secure with you. Be confident that you will know what you will do if the supported person becomes overwhelmed and begins to go out of control. Always have a pre-rehearsed plan for potential crisis situations.

V. How to prepare for transitions and potential crisis situations.

Transitions are often very difficult for persons who are dependent upon explicit prompting.

A. Always have a plan and a variety of methods for orienting supported person to their plan for the day.

Know ahead of time, exactly what is going to be happening <u>next</u>, when each specific interaction is over. Prepare yourself to know exactly how you are going to navigate <u>each</u> transition with the supported person, (between people, places, and activity). Verbally explain this to them. Pre-rehearse with the supported person ahead of time exactly what transitions will look like. (Use picture lists and printed schedules where relevant. Use remnants from the last time you did the activity as a reminder of the "next" time you do the activity.)

For some persons, it is necessary to have a visual and/or printed schedule for each day. Go over this with the supported person so that he/she is able to understand what is going to be happening, and in what sequence.

B. Provide (or impose) an externally organized sense of continuity.

The continuity for every interaction in the day is provided by frequently referring back to the original plan for the day. Keep the supported person focused, within the pre-defined context, about what will be happening, and when. This pre-scheduling gives them "readying to be ready", and <u>time</u> to process in what sequence activities are going to happen.

This pre-scheduling provides the medium with which a caregiver is able to "project" his or her own certainty, and provides the supported person with the ability to "absorb" this certainty and to remain oriented!

C. Be cautious and individual in your approach to giving supported persons "advance warning".

- Some individuals require direct instruction about what is coming up next, and then need to be given time to process, think and ready themselves for upcoming events.

- Some persons benefit more from being able to <u>read</u> about an upcoming event or change than from being <u>told</u> about such activity.

- Some persons benefit most from being asked, "What's next?" to orient them to look at a schedule (once it becomes their "own" idea to look). (This is a good method for people who may react against being "directed too directly".)

- Other individuals will over-focus on an idea or activity from their first moment of exposure. They may be unable to think about or to do <u>anything else</u> until the activity is accomplished. NOTE: Persons with this type of responding to advance notice must not be given any notice till the moment before you are actually ready to do the activity.

Rather than using any one type of "theory" or approach to the person you are supporting, create an "operating manual" for <u>what works best</u> for them. Provide this information to any new people who will be working with them.

VI. How to handle the potential for crisis situations.

Many persons who are dependent, emotionally fragile and reactive "fall apart" if external boundaries are not maintained. If caregivers are inconsistent or uncertain this escalates the supported person’s anxiety and sense of conflict, and can precipitate extreme reactions.

If, as a caregiver, you do find yourself in the middle of a crisis situation, act secure and confident that you know <u>exactly</u> how this will be diverted and calmed. Have a plan, <u>that</u>

was made ahead of time, for what to do if things don't go as planned! Be certain of your "fall back" position. Never be caught unaware or unconfident about how potential crisis situations will be managed.

A. Project your own emotional security onto a person who is emotionally fragile.

Imagine that your greatest success in keeping the supported person stable and focused will come from projecting into him/her your own core certainty that interactions will be stable and focused. You remain stable and focused throughout the interaction. Pay continuous, vigilant attention to the supported person's momentary state of focus and ability to engage in co-operative behavior. You are the "rock" on which the foundation of your interaction rests. You must be secure, confident, and solidly prepared for what you intend to build on this foundation. Know how you expect the individual to be with you!

Imagine yourself as responsible for organizing the supported person's relative strengths and weaknesses. The person's "weak links" (inability to self-initiate, self-orient, self-sequence, or emotional fragility) may make it impossible for the supported person to independently access their areas of strength. It is necessary to support each of the person's weak links and bring these aspects into alignment with their areas of strength.

As the "supervisor-facilitator" to the supported person, narrate your expectations about each aspect of the day, and ready them to be ready to function. Expect them to "absorb" your coach-supervisor-facilitator image of how to accomplish their immediate goals.

Always be prepared to adjust a schedule and expectations to support an individual in a moment of disorientation with additional structure, assistance and guidance.

B. Decompress situations by focusing on routine and ritualistic interactions.

At any time, if things "fall apart", the first "fall back" is to return to the pre-established plan for the day. Refocus the supported person on where he/she is in the schedule. Orient them to what is next. Let them know that they can always rely on you to be consistent and un-ruffled by whatever happens around you. Then carry on with the expected, certain, explicit activity or interaction. Move the supported person onwards. Never look back!

> Know with certainty that as a caregiver you have a plan for keeping the supported person **safe** and that you will be able to show them exactly what he/she needs to do to be successful! This may include calling on additional support to provide necessary limits for an individual whose behavior becomes extreme. A person who is functionally dependent needs to be secure that his/her caregiver will do whatever is necessary to keep everyone safe from harm.

Finally, think about the issue of how to "project into" the supported person your own core certainty.

Work with the supported person with absolute certainty that as their "coach" you are competent to direct them to win “Olympic Gold.” While the supported person is able to orient and engage, keep your standard high, and pre-rehearsed. Know exactly what you expect, what is coming next, and how you are going to bring the individual along with you by working with the specific strengths you observe.

VII. Be prepared for the breakdown in self-control that occurs with "new" caregivers. (Frequently referred to as "the honeymoon is over" or "testing behavior.")

Failure to perceive or to process the important common elements that exist between situations deprives a person of any sense of continuity. This leads to an inability to "generalize" one's experience. It is precisely this failure in the persons we are supporting that results in them being functionally dependent on their knowledgeable caregivers. People who are functionally dependent rely upon learned behavioral rituals, activity routines, and the familiar signals they receive within known social contexts (people and environmental cues).

It is highly unlikely that any new caregiver will be familiar with all of the subtle cues and signals that assist an individual with a developmental disability to "bridge the gaps" in their comprehension and ability to respond. At best, "new" people come to signal the opportunity for uncertainty, conflict and inconsistency. At worst, "new" people come to signal criticism, failure, inability to provide safety, and/or abandonment.

It is almost inevitable that "new" support people will evoke a breakdown in the ability of persons who are functionally dependent to exercise self-control, and regression to more juvenile forms of coping (tantrums and other strategies that brought safety and external control when these individuals were children.) This occurs whenever a person who depends on these is deprived of the opportunity to follow rituals, routines and familiar social contexts. Essentially, "new" caregivers are a signal to a person who is functionally dependent to "go out of control looking for certainty/predictability and control."

A. "Testing" is really "certainty seeking" behavior.

Be prepared for the reality that each new person who works with the supported person may eventually be "tested" by him/her. Testing may be presented in the form of "button pushing". The supported person may do tentative actions, or may do some "out of the ordinary" or disruptive actions. "Testing actions" are presented in the manner of "if I do this, what will you do?" With a person who is "functionally dependent", do not ignore such a disruptive action!

It seems that the function of "testing" behavior with such individuals is to find out if his/her new caregiver is going to be able to "keep me safe from uncertainty". Without solid core, consistent, external boundaries, the supported person may be unable to maintain self-control at moments when he/she becomes confused or stuck in some thought-memory-experience. This type of "testing" seems to be their "rite of initiation" to reassure themselves that the new caregiver will be able to assist him/her to maintain an "Olympic Gold" standard for self-control.

B. How to respond to supported person's efforts to achieve a "certain" response from a new caregiver.

When certainty seeking ("testing") is seen, immediately use the various methods of providing "following guidance". Engage positively with the supported person to give them cueing to maintain a successful interaction with their caregiver. Provide guidance, structure and assistance to allow the individual to be able to orient to positive expectations. Don't wait till the individual has escalated out of control and becomes unable to respond to caregiver cueing. To be a "maestro" with a person who is functionally dependent the caregiver must remain vigilant to the first indication of behavior that does not look perfectly self-controlled. Several examples follow:

- Acknowledge what the supported person is seeing and hearing in the immediate "here and now". Narrate their immediate experience. (E.g., "The glass fell over. The water is running off the table. The cloth is drying it up.")
- Perhaps offer yes/no choices to assist him/her to explain what is on his/her mind.
- Perhaps ask him/her to "show me" what they need.
- Acknowledge that the supported person is experiencing a momentary disorientation. Say, "How you doing?"
- Express your interpretation of the supported person’s frustration and offer him/her a "way out".
- Either go on with a refocus on your previous plan for the day, or call for backup with a "new face" to assist the supported person to make a positive reorientation.

The suggestion is to always plan for such certainty-seeking ("testing") behavior with new staff. It is suggested to have more experienced caregivers "shadowing" any new staff and the supported person the first several times that they are alone together. This will give new staff reassurance that "back up" is immediately available.

> NOTE: Some individuals who are functionally dependent are disoriented if there are two caregivers in their immediate environment at the same time. They become confused or in conflict about which caregiver's cues they are supposed to follow. Be alert to this possibility. Sometimes the "back up" may need to be out of sight until needed as a "new face" to reorient the supported person.

This level of extra support will give the supported person the experience that if he/she does not respond to expectations from "new" staff, this will be immediately backed up by external boundaries imposed by a caregiver who is much more certain.

> NOTE: Experienced caregivers may be having their own anxiety about how well a "new" caregiver will be able to provide support. This will be reflected by a person who functions like "emotional radar", and will undermine their ability to respond to the new caregiver. It is important for experienced caregivers to project their confidence that the "new" caregiver will be able to successfully provide support.

CAUTION TO "NEW" CAREGIVERS: A high level "independence" you see in your "new" individual you are supporting may actually be "dependently-independent" behavior that was developed over a long period of time, with extreme supports. Don't make assumptions about what a "new" person to you should be able to do on their own. First, find out what it takes to support this individual so that they can be successful. Protect the individual you are supporting for the first time from becoming over-extended. Be prepared to listen to those "old" caregivers that advocate about extra supports that are required on the basis of their long-established relationships. Being "over-focused" on the individual's needs may keep people from being hurt.

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End part two of three.

NON-COMPLIANT AND/OR NON-RESPONSIVE? ALTERNATIVE REASONS WHY THIS OCCURS IN PERSONS WHO ARE DEVELOPMENTALLY DISABLED

SOURCES OF FUNCTIONAL DEPENDENCE

NOTE: The factors mentioned below are not related to the degree of developmental disability or "level" of intellectual handicap. These factors can be observed in "higher" functioning as well as "lower" functioning individuals. Multiple factors may be shown by any particular individual. When these factors occur, they are "facts of life" for the persons affected, and influence all of a caregiver's interactions.

1. SENSORY FACTORS:

Some people have little capacity to "attenuate" or regulate their emotional and physiological responses. They have overly large reactions to relatively minor amounts of stimulation.

A person may be "tactile defensive" to any degree of physical contact around their head, face and mouth. Approach by caregiver "triggers" defensive, protective reaction. (Long-term desensitization approaches are required.)

The level of stimulation in their environment may easily overwhelm such people. People may be so over stimulated that they are unable to process a direction or request. To protect themselves, they may engage in defensive avoidance. (At early signs that too much is going on for person, cut back expectations and slow things down.)

For some people, if a request or direction causes confusion for any reason, the experience of confusion may be an extremely aversive experience, evoking fear or intense emotion. Confusing requests or directions cause over-arousal, leading to over-reaction or panic. (It is necessary to protect these individuals by rigorously organizing and regulating their environments to keep things predictable and at a tolerable level of stimulation.)

2. MOTOR FACTORS:

Some people engage in motor perseverations. These are meaningless, repetitive, continuous physical actions that may self-distract or prevent the person from being able to respond to direction or requests. Engaging in these actions often becomes like self-hypnosis and "breaking" these actions can evoke arousal and panic. (It is necessary to find methods for engaging with person without startling them or causing them to become disoriented.)

3. COGNITIVE FACTORS (What the heck does that mean.): These are "mental handicaps".

A person may be attending and hearing what is requested but is not able to process the meaning of the language being used. They are trying, but can't "get it".

"When?" "Where?" "Who?" "What?" "You have to show me!" Some individuals may have difficulties processing communication relating to time (past and future tense); sequencing-"later-not until then" & before-after concepts; and comprehension of indirect references to space and place (prepositions/pronouns="where?/who?"). (It is necessary to speak in the "here and now", to use exact-concrete references, and to point or use pictures or writing when referring to non-present people or situations.)

Living in the "here and now". Little sense of "continuity": Some individuals appear to experience things only in the immediate, "here and now". Each of their experiences is discrete, as though it is happening to them for the first time! (With these persons, "out of sight" is truly "out of mind".) These individuals seem to experience discontinuity or disconnectedness between their experiences. They do not modify their behavior on the basis of their experience. They don't perceive the connections or relevance between similar experiences.

> *"All or nothing" learning:* When they do learn, it appears to be an "all or nothing" experience. It seems that sometimes things just "line up in a straight line" for the individual and they can instantly perceive the whole picture, and know exactly what to do! They perceive what is required and learn, in one experience, what they need to do to be successful. This gives the impression that "they are so smart they could do anything". The problem is that the person may be unable to control when they will "get it". They may have dozens of repeated experiences and still display no learning whatsoever.

Jumping to conclusions. Getting things "half right": Some supported persons may be unable to "get the picture" until they know everything (unable to tell the "whole" from "parts"). This may result in constant question asking. They may "jump to conclusions" on the basis of partial information which they use to "invent a meaning" for themselves (unable to discriminate relevant from irrelevant.) (These individuals are good at persuading caregivers that they understand. It is necessary for caregivers to not "jump to their own conclusions" about what the supported person has actually understood. Check it out. Give the supported person all the information they require to "get the picture.")

> An inability to "get the picture" results in supported persons who may be unable to independently apply their cognitive skills to ambiguous situations. They may be impaired in any situation that requires them to analyze and determine what type of response is required of them. (The result is that the supported person could be independent in applying skills in familiar situations, while at the same time having no ability to deal with any unfamiliar social setting.)

What you "see" is not always what you "get". There may be unique difficulties with attention span (how long they can concentrate); distractibility (how vulnerable is their ability to concentrate); or with the amount of information the individual can hold in their immediate memory at one time. The supported person may have great long-term memory and may speak in full sentences, but themselves only be able to process a few words at a time. These factors will affect an individual's ability to process more than one piece of information at a time. (It may be necessary to talk in shorter (one-part) sentences or talk slower, and repeat yourself several times.)

> These disabilities require presenting your communication in a more "simple" form, without "talking down" to the supported person.

A person may be able to process written or pictorial information (which they can repeatedly focus on as they are ready) much better than oral information.

Hard to believe, but none-the-less often true: These "cognitive factors" are often "invisible" to caregivers, and only show up through specific language and psychological assessment. These factors frequently show up in a functional analysis of behavior. These are the repeated situations where supported persons almost always require "bridging" by a knowledgeable caregiver. When experienced caregivers are aware of these "invisible handicaps" it is necessary to advocate for the supported person with new caregivers or with others in their support network.

It requires persistence and consistent work by caregivers to support individuals with these cognitive disabilities. Even more difficult is how hard it is to believe that these "invisible handicaps" exist and that they can be so totally disabling, rendering the supported person functionally dependent in the affected areas. It is easier to do what needs to be done, than it is to believe that what needs to be done, has to be done for the affected individual to be able to cope!

4. MOTIVATIONAL FACTORS: PERCEPTUAL AND ATTENTIONAL FACTORS:

Another source of functional dependence can be that the supported person is distracted and not attending, orienting or focusing on request or direction. This makes the caregiver’s directions irrelevant, as they are not perceived. (It is necessary to find ways to "capture" the supported person’s attention.) Several things affect attention:

Comfort level: A person may be involved in familiar, ritualistic behaviors, which is how they organize their time and activity. These maintain the person's comfort level. (Let the person finish what they are doing, and then they may be prepared to do what you are asking.)

Interest level: A person may be engaged in something else that fully captures their attention. They are "busy" doing something else that is important to them. Caregiver’s request or direction is not important enough or valued enough to capture the supported person's attention. (Increase the value to person of request you are making.)

Consciousness level: A person may be unable to attend until they are "readied" or oriented to respond. The person may be unable to respond until it becomes his or her "own" idea. (It is necessary to find a method to put the request or direction into the supported person's <u>own</u> framework, or point of view for them to be able to perceive this.)

Self-concept; fear of failure level: A person may <u>want</u> to do what caregiver asked but doesn't think they are able to do it successfully, thus avoids or resists the potential for failure. (Set things up so that the person can perceive that they know exactly what to do to be successful. Lower the expectation for the <u>amount</u> of things that are to be accomplished. Raise expectation for the <u>perfection</u> with which fewer things will be done. Provide as much support as is necessary to accomplish this.)

Mood factors: A supported person may be so emotionally depressed that they could not be motivated to respond if the house was on fire. (See mental health factors, below.)

5. BEHAVIORAL-EMOTIONAL FACTORS: CONTROL ISSUES:

Behavioral: A person may simply not be interested, not want to do what is requested and avoid responding. It's too hard or not worth the effort. (Increase the value to the supported person and make things "easier" to achieve.)

Self-concept; desire for independence: An individual wants to do things their own way and resists direction or requests from others. The supported person has his or her own ideas. For example: "I'd rather do it myself". Or, "If it's <u>your</u> idea I will probably say no, even if I really want to do what you are asking." (Caregiver should make requests and directions as "choices" which the supported person may make, on their own initiative. Caregiver gives the supported person the "answer key", where all choices, which you provide, are achievable. They make the choice. Every choice is "correct"!)

Self-concept; desire to avoid external control: A supported person may not want to be directed or controlled and reacts against caregiver's direction. The person doesn't want the caregiver's influence. For example: "You can't tell me what to do". "You can't make me." (Try to rely on impersonal, objective 'house rules' that fairly apply to everyone. Rely on rituals and routines that the person can predictably use as a means of self-regulation and self-control.)

Cognitive-emotional process: The supported individual may be unable to independently focus their own actions, but is quite able to do so <u>in opposition</u>. Being oppositional is the only way they are able to maintain a sense of control. (Don't be a sail in their wind. Withdraw from conflict and they lose their ability to resist. "Change channels" and come back later.)

6. LEARNING HISTORY: CONDITIONED EMOTIONAL REACTIONS

Request or direction is associated with some previous aversive experience which "triggers" reactive-opposition. (Don't be a wind in their sail! Be aware of sensitive words and issues and avoid provoking these. Protect person from having to deal with these situations.)

The individual may have a situational, learned panic reaction to tasks, people, places, phrases, over-stimulating experiences, etc. (Don't expect a person affected in this manner to be able to "deal" with these intense emotions. Assist the supported person to depart these situations.)

The supported person currently anticipates that they will be in distress in certain situations that were previously aversive, e.g., crowds or certain people. (Avoid such situations and retrain emotional reactions by careful desensitization to these situations.)

7. MENTAL HEALTH FACTORS: PSYCHIATRIC INVOLVEMENT

ANXIETY:

An individual who is experiencing conflict, confusion and fear of failure typically decreases in their ability to focus their attention, to solve problems or make decisions and may become non-responsive. (Diminish the choices that are offered to affected individuals; simplify and slow things down. Re-anchor person in familiar routines.)

A supported person may be experiencing "free floating" anxiety with no specific cause. (Give continuous reassurance and assist person to feel safe.)

DEPRESSION:

The individual may be involved in a reactive depression associated with some significant personal loss. (Acknowledge the natural grieving process and support accordingly.)

The supported person may be inwardly involved in their state of woe. Their responses to their environment may be muted, their ability to problem solve or make decisions may be diminished. (Support the affected person with extra assistance. Protect them from conflict. Simplify and slow things down.)

A person may be overwhelmed by a sense of shame and self-blame and feel helpless to do anything about their situation. (Engage in therapeutic relationships to "take away" shame and self-blame.)

MANIA:

A supported individual may be in an altered state of consciousness. They may become hyper-reactive and overwhelmed by stimuli. They may be experiencing a flight of ideas and may be only partially processing what is said to them. (It may require close supervision and intense support to keep a person safe during a manic episode.)

NOTE: For all of the mood disorders it is important to use cognitive and behavioral approaches where these are relevant. Sometimes, cognitive and behavioral approaches can only go "so far." It is often necessary to make use of psychiatric medications to assist some supported individuals to cope with these disorders.

OBSESSIVE-COMPULSIVE RITUALS:

The supported person may be doing meaningful behavior that is necessary for their "psychological survival." They cannot stop the action without escalating their anxiety into a state of panic. (Keep their world in a routine and predictable structure.)

DISSOCIATION-PHOBIAS-FEARS:

A supported individual may be in an altered state of consciousness. The supported person may not be experiencing the "here and now". They may be reliving some past experience of trauma and are non-responsive in the moment. (Focus person to "here and now" and feelings of safety and security. Engage in long-term counselling and eventual desensitization.)

PSYCHOSIS:

A supported person may be in an altered state of consciousness. For example, they may be having an auditory hallucination and become engaged in a conversation with someone or thing that the caregiver cannot see. The supported person may be angry and resistive towards the caregiver for interrupting their conversation. (Don't intrude. Wait for permission to interrupt.)

PERSONALITY DISORDER: (Cluster B):

The supported person may do fine while they are "centre stage" and everything is going their own way. At any moment when they feel threatened they may display any of the mental health or other factors that are sources of functional dependence.

PHYSICAL OR PHYSIOLOGICAL CONDITION:

Depending on their physical and physiological condition, some persons with developmental disability and/or organic brain dysfunction may experience fluctuating levels of consciousness and fluctuating ability to respond. Some examples that can have this effect:

Insulin levels, Thyroid levels, Medication levels (toxicity)
Seizures, pre and post seizure states
States of pain (toothache, earache, menses), Infections (bladder), Allergies
Fatigue, Hunger, Level of physical stimulation (too much or too little)
Condition of shunt (arrested hydrocephaly), etc.
Physical syndromes

Physical changes may cause an individual to become momentarily disoriented or disconnected and functionally dependent on a caregiver to assist them to cope.

Refer to attachment by Developmental Disability Mental Health Team on "Things to remember when someone is in a mental health crisis."

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End part three of three.

THINGS TO REMEMBER
WHEN SOMEONE IS IN A MENTAL HEALTH CRISIS

♠ They may not be able to be rational.
♠ They may not be able to process verbal directions.
♠ They may be overwhelmed by any sensory input.
♠ They may not understand or be able to resolve any conflict, or contradiction.
♠ They may not be able to properly process any emotional messages.

This includes non-verbal facial expressions and body language.

These may overwhelm or confuse them.

♠ They may feel abandoned, angry, confused, disoriented, lost, anxious, overwhelmed, out of control, threatened by what they don't understand, and helpless.
♠ They may be desperate to make contact to anchor themselves to some reality that they can understand.

They may be unable to sustain these contacts.

WHAT CAN YOU DO?

Keep it easy, low key, simple, direct, explicit, and accepting, while still giving the safety, security and guidance they require.

♠ Do not engage in their angry, verbal outbursts. Repeat, "We are here to help you and keep you safe."
♠ As needed (prn) medication should be given at first signs of escalating agitation or self-abuse.
♠ If self-injury is a problem, explore positive prompts that may bring them out of it, i.e. "breathe", "let's go for a walk", or use prn.
♠ Whenever hands on physical contact is required, be fair and supportive.
♠ They may benefit from being in a reduced sensory environment so that they are not obliged to sort out their sensations.

Keep it quiet, comfortable lighting, etc.

♠ Keep verbal interactions and directions simple, clear, using a minimum of words.
♠ Asking for them to make decisions and choices may be very stressful, and add to their confusion. Establish a routine and stick to it. **Time is not as important as the sequence of events in the routine.** Tell them what they need to do next, or what you are going to do next. If they react, that's okay. Protect, support, and try again when settled.
♠ If person is likely to run away from their support person, have a pre-established, written protocol for who must be contacted and where to look first.

These are guidelines only to help develop approaches specific to each individual's needs.[♥]

[♥] Prepared by Developmental Disability Mental Health Team 2001.