

CONFRONTING CHOICE: CONFRONTING CHANGE REACTION OR RESPONSE

A Necessary Introductory Dialogue

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No discussion about FASD and adolescents and adults can be undertaken without a discussion about how ‘what to do’ when confronted with behaviour misinterpreted as ‘choice’ rather than the result of a neurological deficit. This misinterpretation impacts on our individual functioning. The ballooning numbers of individuals with FASD entering adulthood will impact profoundly on *every* system we have, and will do so for many, many years to come.

Choice in how an individual behaves, and choice in what we do about it are two very different things. Every person who parents effectively or works on the front lines with teens and adults with FASD *knows* that there is no “choice” in the behaviour of those individuals; that “things just happen”. There is little, if any, real planning, and rarely is there intent connected to actions that lead to a multitude of negative outcomes. No one is more confused, bewildered, upset, angry and resentful than the adult with FASD, who has been, once again, accused of something not at all intended, and for which the consequences are not understood. They are most frequently ineffective and will not likely be remembered.

In comparison, we, on the other hand, are capable of planning, intending, understanding the consequences and following through with actions. We are capable of deciding what it is we *will do, or will not do*. Our difficulties related to coping with behaviour lie in three areas: (1) not knowing the differences between a response and a reaction; (2) not understanding how and why we cross the line from one to the other in our personal work with adolescents and adults with FASD; and (3) not moving both publicly and politically to effect needed, systematic and systems-wide change to provide services that respond to clearly identified need.

If one looks up the word *reaction*¹ in the dictionary, you will note some interesting definitions, with the underlined emphasis being mine:

- (1) “an action in opposition to a force or influence – usually used with against”;
- 2) “tendency toward a former and usually outmoded political or social order or policy”;

¹ Merriam Webster’s Deluxe Dictionary, 10th Collegiate Edition (1998)

(3) depression or exhaustion due to excessive exertion or stimulation; heightened activity and overreaction succeeding depression or shock;

(4) a mental or emotional disorder forming an individual's response to his or her life situation.

If one next looks up the word *resentment*² you will find the following: *a feeling of indignant displeasure or persistent ill will at something regarded as a wrong, insult or injury*. It is interesting to note that the word “resentment” comes from the French word “resentiere” which means to “*re-feel over and over again*”.

If one then looks up the words *response* and *responsive*³, you will find the following: (1) *something constituting a reply*; (2) *the activity or inhibition of a previous activity of an organism or any of its parts resulting from stimulation*; and (1) *quick to respond (or react) appropriately or sympathetically*.

I think the problem for all of us – affected adolescents and adults, those who are parents of adults and those who work with adults – lies in the “**depression, exhaustion, excessive exertion, heightened activity, overreaction and shock**” we all face on a daily basis. This forms the “**mental or emotional disorder**” of our “**individual life situations**” and is in no small measure related to the “**outmoded**” “**social**” “**policies**” related so significantly to the poor outcomes for those with FASD. As parents, this “**emotional disorder**” may be what prevents us from learning *and applying* new ways to respond more effectively to our adult children. As front-line workers, it may be what does not allow one to take risks, do things differently, outside of “**policy**” or develop creative, if not quite ‘legal’ solutions. Parents, advocates, mentors and front-line workers who are seen as “**against**” the system or family, or “**oppositional**” in their dealings with it, may be so primarily because their personal experience is that there is nothing to be “for” or to offer, that is helpful, supportive, effective, cost-neutral and long-term. They are reacting to families or systems because they cannot respond to those they need to serve, or families to their children, without the aid of systems who do not have the resources to help them do so. Their anger is a mask for their pain.

The “resentment” we all feel is not at FASD, or individuals with FASD, *once we understand the disability*. The resentment we feels is not towards front-line workers, or at parents, *once we understand the effects of the disability on others*, but at the generic, all-encompassing “system” that does not, will not, and in most cases at the present time, *cannot* address the critical needs of adolescents and adults with FASD because it is not able to. To say that the “**displeasure**” that is felt is “**indignant**” and only “**displeasure**” is to put it mildly. The “**wrong, insult and injury**” done to both the affected individual and his/her family and to front-line worker due to the absence of services for them to use as a tool is what leads to the feeling over and over again that is so acutely, “resentment”. One can feel a

² IBID

³ IBID

negative emotion or pain only so many times. The cumulative effect becomes profoundly damaging and disabling to those from whom we expect to receive support and on those who need to receive support. Apathy, anger, shame, withdrawal, detachment, disinterest, running away and quitting become the norm. These may be the only ways in which people can protect themselves from the magnitude of what they face when not effectively and adequately supported. The cycle of deficit-based-need, lack-of-ability to respond, reaction and resentment (both internalized and/or externalized) leads to greater and greater need and resentment, spiraling ever more broadly out of control for everyone involved, in all capacities.

The place where we can begin to alter what we do lies initially in the recognition of these factors. However, and more importantly, it also lies in recognizing that we, each and every one of us, are the “system”. And that means we can change our minds. Individually, collectively, emotionally, socially, morally, financially, legally, politically, and in every other way, together we control what happens. We have the power to determine what the priorities are, or *can* become, should we choose to do so.

We need to begin the process of responsibly exercising that power. The time to do so is now. We are *out* of time.

We are, realistically, facing a time of crisis with respect to the aging of those with FASD. The acuteness of their need, the significant financial outlay that will be required far into the future, the commitment of time and personal resources, and the need to do things very differently from what, to date, has been the norm must be recognized now.

“Crisis” is the Greek word for *change* and the Chinese word for *opportunity*. If we can keep this in mind, then the crisis becomes an opportunity for real change. Crisis can move us from a reactionary system to a responsive system; from systems trying to “put out fires” at great cost to preventing them from occurring in the first place, at a lesser cost. To quote Dr. Christine Looock “It is far cheaper, and makes more sense, to build a fence at the top of the cliff than to park an ambulance at the bottom”.

Together we can figure out and learn – individuals with FASD, families, mentors, professionals, front-line workers and systems working cooperatively, collaboratively, respectfully and *equally* - how to “*inhibit the previous activities*” To stop what does not work. Too *reply* by doing what does work better. *Quickly, appropriately and with empathy*, - “to build the fence” - to improve the quality of life of all of us.

We all deserve that.