

MANUAL FOR CLASSIFICATION OF THE REACTION TO DIAGNOSIS INTERVIEW

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University of Virginia

Version 1.0

Draft 4-1-93

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General comments and background information

This manual and the accompanying Reaction to Diagnosis Interview, for which the manual was designed, is intended for research use with populations of parents of children with some form of disability or chronic illness. The Interview was designed to measure parents' reactions to and coping strategies for dealing with, the diagnosis of their child with a disabling condition or illness. The Interview consists of a series of questions eliciting the parent's beliefs, memories and emotional reactions to the news of their child having an illness or disability. The Interview takes approximately 10-15 minutes to administer and the interviewer should be trained in the administration of semi-structured interviews in general, and the Reaction to Diagnosis Interview specifically.

This Manual was designed to code parents' responses to the Reaction to Diagnosis Interview. In particular it codifies the parents' representational, or mental, models of the child with the disability or illness, and the extent to which the parent has resolved the trauma of the diagnosis and diagnostic process. This Manual and coding system is in the early phases of development, having been used with parents of more than 60 children with disabilities and chronic illnesses (cerebral palsy, mental retardation, epilepsy). Validity data indicate that the classification of Unresolved or Resolved, based on the descriptions in this manual, is strongly related to the classification of the child's attachment (secure, insecure) to the parent (Marvin & Pianta, 1992; Pianta & Marvin, 1993). In a study of 57 children with cerebral palsy between the ages of 15 and 50 months, in which all were seen at least one year post-diagnosis, 30 mothers were classified as Unresolved, and 27 were classified as Resolved using this Manual. Looking more closely at the link between Resolution and child-parent attachment in 33 of these children, 11 of the 14 mothers classified as Resolved had children with Secure attachments; 16 of the 19 mothers classified as Unresolved has children with Insecure attachments. The overall hit rate between child-parent attachment and mothers' classifications as Resolved or Unresolved with respect to the child's diagnosis was 82% (Chi-square 8.79, <.01). Current work with the Reaction to Diagnosis Interview involves 80 families of children with cerebral palsy, 40 families of children

with epilepsy, and 25 families of children with a cranio-facial anomaly. In this work both mothers and fathers are administered the Reaction to Diagnosis Interview (separately) as part of an extensive interview and observation-based study of parent-child and family relationships in children with these conditions.

The coder should be completely familiar with the Reaction to Diagnosis Interview and have administered it on several occasions before attempting to code. Several aspects of coding depend upon some interpretation of the parents' interaction with the interviewer and the interviewer's feelings about those interactions. Also, the coder should understand that although the classification of Resolved/Unresolved is made based on the parents' response to all questions, there is the possibility that certain parts of the interview, or the response to certain questions, should be more heavily weighted than others. This may vary across cases, but also we find that answers to the question of how the parents' feelings have changed over time are important in determining resolution. It may also be important for coders to decipher male codewords for emotions and emotional experience.

We make the assumption that becoming aware that your child has a medical problem, and receiving a diagnosis of a somewhat serious medical condition (such as cerebral palsy or epilepsy) is a crisis for a parent and threatens (destabilizes) their view of their child, themselves as parents, and parenthood. This information pairing the child with a developmental or medical problem (this information could be the parent's observations, the child's behavior, or others' impressions) is not wanted to be perceived by the parent, and is accompanied by feelings of threat, crisis, and trauma. The parent may actively "push away" this information and exclude it from awareness, as many of our parents report. This impulse toward dissociation is normal in a period of crisis.

Resolution is the process of the integration of this information/emotion within the parents' representational systems of themselves as parents, of their child, and their relationship with their child. The cognitive task of resolution is for the parents' mental representational systems to integrate this information about the child and incorporate it into without distorting reality, for example by denying the child's true condition (minimization), or focusing too much on this information to the exclusion of other (present-day) realities (stuck in the past and preoccupied). Furthermore, the emotional work of resolution (which goes hand in hand with the cognitive work) is to acknowledge the pain and feelings associated with this news and the ongoing experiences of parenting a child with a medical or developmental problem. This involves again a lack of distortion of the feelings (not changing pain/sadness to anger at the medical system - a displacement reaction), a focus on the present reality (feelings do not disorganize the parent, an acknowledgement of an emotional "moving on"), and a move away from feelings of crisis to feelings of coping (e.g. not devastated anymore but sad from time to time).

Fundamentally, resolution of the diagnosis occurs when the person indicates that the crisis of the diagnosis is over and they have moved on with the job of parenting a child with a disability. However, for parents of a child with a disability, the "crisis" information and feelings periodically (for some more than others) surface as challenges to the representational model's equilibrium and the cognitive and emotional work of resolution will be re-engaged. We suspect that for most parents this is an ongoing, daily process that occurs on the edge of awareness, with periodic efforts that require more active, conscious coping. Therefore, resolution is viewed as a process, and the extent of resolution will vary from time to time depending on the child's and parent's circumstances, as well as developmental history.

There is reason to believe that some diagnoses may be more prone to lead to lack of resolution in the parent. For example, in our samples, although cerebral palsy is a possibly devastating condition, it is in itself a static condition. It is a fairly "known" entity and once the parent begins the process of resolution, the diagnosis of CP itself will remain fairly stable. On the other hand, parents of children with epilepsy report epilepsy as a much more volatile and unstable condition. There are times when the child remains seizure-free for long periods, then relapses into seizure activity. Almost all parents report having to deal with the fear of recurring seizures, the fear it will get worse, at the same time dealing with the reality that some children do grow out of epilepsy. This seems to us to be a potentially more difficult set of circumstances in terms of the tasks of resolution.

We interpret lack of resolution similarly to Mary Main's concept of lack of resolution. It is noted that when an attachment figure is "lost" that the individual goes through a stage of mourning or grieving during which active attempts to search for or replace the lost figure predominate the individual's attachment system. Much like individuals with Post Traumatic Stress Disorder, individuals who are in this stage may experience some form of cognitive disorientation, "flashbacks" to experiences with the lost figure, or fugue states. Again, as Mary Main states, the key to resolution of loss or diagnosis is the acceptance of reality and then a termination of the search behavior and re-orientation to everyday life and its tasks. For the parent of a child with CP, the "loss" is symbolic, nonetheless also very real, and this is not a loss of an attachment figure so the parallels with work on loss of attachment figures is not exact. Nonetheless there are very real parallels with the grieving process and the notions of resolution. There are MANY ways in which a parent can indicate resolution or lack of it. The coder should be alert to the fact that there are multiple patterns, and that many persons will not purely "fit" any one pattern. In fact, it is very likely than any given person will show elements of both resolution and lack of resolution. The coder should carefully identify all elements present in the interview, then return to watch the tape and judge resolution at the "forest" level, by deciding whether the "package" of elements present in the interview indicates the parent fits the general description of someone who is "on the path" toward resolution or not. This is not to be equated with the parent who oscillates between resolution and lack of resolution (unresolved) or the case in which the "mixture" of elements presents in such a way as to indicate the parent is "stuck" in the mixed patterns (unresolved).

SIGNS OF LACK OF RESOLUTION

The following indicators are definite signs of unresolved parents. They must be present when an interview is coded as Unresolved, but they may also be present at a lower level in interviews coded as resolved.

Parents whose interviews are classified as Unresolved have in common the "disorientation" found when a person is grieving. The process of disorientation in this population refers to the mind being focused on something other than the cognitive and emotional realities of the DX - this may involve cognitive distortions of the Dx, a focus of attention on the search for a reason, the person being focused on the past in some way, or emotional signs such as being excessively overwhelmed or depressed, angry (indicating an emotional focus only on the pain) or emotional signs such as being cutoff from emotion, focused only on the self, the benefits of the experiences (for self or child or others) or denying emotion (all indicating an attempt to deflect emotional reality). All of these prevent the parent's perceptual systems from focusing on the reality of the child's needs (feelings) and cues (signals), therefore we predict that these patterns have negative consequences for parenting and for the child in the sense that information from the child may be distorted, filtered, ignored or amplified in such a way so as to prevent sensitive, balanced responses. We predict that certain specific child cues may be particularly problematic for the unresolved parent, especially those that most directly and unequivocally pair the child with the disabling condition (one mother puts her child in beauty contests).

1. Signs of cognitive distortions.

These signs have in common the parents' attempts to distort reality through the use of unrealistic beliefs or expectations, or blatant non-acceptance of reality and pursuit of fantasies or wished-for realities.

- Parent has not accepted the permanence of the child's diagnosis or condition. Parents may be still involved in a search for a (different) diagnosis even when all the evidence (and they have received a diagnosis of CP already) points to CP. Other parents may indicate they believe the child will grow out of the CP condition. Still others may indicate unrealistic expectations for their child in the face of very strong evidence to the contrary, such as the mother who expects her child to be a brain surgeon and help other children with CP even though he is uncommunicative at age 2.5.

- There may be several signs of unrealistic expectations or hopes. The parent may expect the child will "grow out of it", or may have unrealistic hopes for the extent to which the child will attain a normal life in spite of the CP.

2. Continued search for reasons for CP or unrealistic stance re: reasons

Common to those in #1 above, these parents remain engaged in a search for the reasons why their child has CP. In some way they acknowledge the CP but displace their wishes for being rid of the CP onto the search for a reason or an explanation. This focus distracts then from the reality of their child's condition. There may be signs that the parents say they think any number of things may have caused it, or they wished they knew what caused it, without any indication they accept that there is no answer. Also, parents may have unrealistic beliefs about what caused the CP or give reasons that indicate they were involved directly or indirectly in causing the CP thereby maintaining some feelings of guilt.

3. Parent disoriented by being "stuck in the past."

In the case of the parent being stuck in the past, fundamentally we see the parent reliving the diagnostic process in the present day. This is not to say that resolved parents do not have memories of the diagnostic process, discuss it with some emotion associated with that period, or have wishes to undo the past, but what distinguishes the resolved from unresolved parents with respect to this issue is that resolved parents are focused on the past, they do slip into present tense when discussing the past, they do not enlist the interviewer in feeling their experiences or seeing the past the way they do.

Some subpatterns within this pattern:

a. The parent may be emotionally overwhelmed by the past experience, discuss it as if she is reliving the past with ALL the grief and pain associated with that overwhelming time. One mother is a good example of this. The parent is clear that this all is happening "just like it was yesterday."

b. The parent is angry and presents the anger and her story to the interviewer with a feeling as if she is trying to enlist the interviewer in seeing at she sees it and justifying her anger. The anger is present and made so through slips of the tongue, lapses into present tense, failure to mark dialogue and tone of voice (refer to Main's passivity of thought and thematic anger scales for the Adult Attachment Interview). Much of this anger is usually focused at the doctors and what they did wrong. Many parents have very justifiable feelings of anger toward doctors and the medical system that may have handled diagnostic processes or procedures incorrectly. However, many resolved parents describe these feelings and experiences with complete reference to the past, as if they were encapsulate experiences that they have access to but do not bring into the room. Lack of resolution is signalled by anger that is thematic and that does not seem to lead anywhere in the interview, for example, the parent continues to return to her "story" complete with anger, after she has already shared it.

c. Finally, the parent may have a focus on her self - on herself as a survivor of this experience, as if she recognizes the trauma of the experience but has come to wear the trauma as a badge - that is the child; diagnosis has been used as an organizer for the parent's identity - the parent's sense of self is that she is a parent of a child with CP.

4. Evidence of confusion and mental disorganization

Some parent present with such incoherence and disorientation (that is focus elsewhere) that it is very difficult to understand their story and to discern what the story is. These are parents who may have been repeatedly traumatized and the diagnosis is simply one more trauma, but in any case, there are many routes to this form. The characteristic feature of this pattern is confusion and incoherence in presentation such that the interviewer has great difficulty understanding the story. These individuals lose their train of thought in the interview have great difficulty seizing on an answer to a question and may contradict themselves or be unable to come to a definite response. They may not ask clarifying questions.

One parent showed off frowns (as if at herself), swings of her head as if to try to orient herself to the present, exaggerated caricatures of concentrated thinking, appeared quite incompetent and seemed to want to present herself that way.

5. Cut off from the experience of the diagnosis.

These individuals appear shot down or cut off from the emotional and to an extent the perceptual experiences of the diagnosis. They cannot report about their experiences because they do not have memory for them. This is certainly true of their feelings and may also be true for their perceptions- that is they will not be able to talk about how they felt and they may also not be able to report what actually happened. They simply cannot discuss the topic.

6. Denial of impact of diagnosis on self.

These individuals appear cut off emotionally from the experience or minimize the emotional impact of the diagnosis (it wasn't that bad, it didn't bother me) the attempt with these individuals seems to be to keep attention away from the emotional impact of the grief on the self. These individuals may have excellent memory for the vents around the diagnosis, what they did, how well they coped, and may even acknowledge some aspects of difficulty (it was hard to get and answer) but they are very clearly avoidant of emotions, especially with those linking the self with the child's diagnosis.

7. Displacement reactions

This is conjecture based on M Main's observations re: loss. There may be parents who report some unusual displacement reactions - that is energy that seems best connected to the child's condition is directed elsewhere and the parent seems unaware of the connection. For example, in the epilepsy project we had a mom with a child with not very well-controlled seizures go back to school to become a nurse specializing in pediatric neurology, yet she never made the connection with her child's condition.

Other notes regarding lack of resolution of the child's diagnosis.

Much of the content of the Rx to Dx interview is sad - therefore the expressions of affect the parent shows may be important indicators of their mental state. For many parents uncomfortable with the Dx we see laughter during the interview that feels and appears incongruous with the content. For some parents it's a way of dismissing (instead of accepting) their own sadness about the child, for others it can be laughter at the child or situation. It is important for the coder to look at all verbal and nonverbal expressions of emotion and determine their congruity with the content of the interview at that time - incongruity is seen as evidence (not necessarily strong evidence) for lack of resolution. This incongruous laughter is different than using humor in the situation and the "stuff" not being in the present. Unresolved parents often use laughter to back away from the intrusion of the material into the present situation.

Be careful about differentiating between the parent inducting the interviewer into the parents' story about the doctors (may be a reality base for this) and inducting into the parent's own pain - here we see a difference between the story about doctors and the story about the parent and child and we are more interested in the story about the parent and child.

Unresolved parents often will enlist interviewer in an effort to see their story (about child or many times about medical system) as they see it. There is considerable effort expended toward this goal and parents' efforts are resistant to pressure from the interviewer, there seems to be need on parents' part to gain a shared perspective with the interviewer that will justify the parents' feelings and beliefs.

Watch for very rapid shifts in topic in response to a question that may elicit feelings - so rapid a shift that the person may not take a breath or pause between words. This appears to be an effort to move away from the pain of the discussion.

There may be an Unresolved/Neutralizing strategy in which parents don't dismiss the emotions and events of the diagnosis in the sense of moving away from them but instead recount lots of the events in great detail but seem emotionally disconnected from the meaning of the events.

Watch the nonverbals parents use in response to stress - do they put their hands in front of face, squirm in chair, wring hands, etc. these are signs the parent is under stress and may be keys to watching how they handle the stress. Does parent start nodding before the question is even answered (suggesting a formula response) or does the parent sit up as if to leave during the interview (suggesting a wish to escape).

Watch for boundary-negotiation by parent - does parent assign the interviewer to an intimacy status inconsistent with their position as a professional? Is there an effort to pull the interviewer in to take care of parent?

Indications of guilt in the reason why the child has CP question should be taken seriously by the coder. One parent to date has been in a car accident which resulted in cp for her child but she was able to describe it in very understanding and balanced terms - yet other have identified some form of personal salvation or personal growth as the reason why they were given a child with cp (the existential question) - these reasons are different from those parents who say they have grown as a result of raising a child with CP. The difference is in seeing your actions as the reasons for the child's cp.

Watch for the parents' use of words. Some parents use the label (CP) and substitute it for the child, others will talk about "the handicapped" but not talk personally about their child. these are clearly efforts to distance the self from the child and the diagnosis. Still other parents will use jargon "just have to deal with it" over and over and over again in the interview, often instead of sharing details about experience. In these cases jargon serves the purpose of deflecting attention from the reality of the condition.

Some "pat phrases" serve to deflect the individuals attention away from pain but do not diminish or derogate the emotional experience the way some slang terms do (e.g., hunky dory).

It may be significant that some persons stay focused on the details of the story and share nothing about their personal experience.

Some of these persons who appear dismissing during the interview with regard to feelings and experiences may also focus on caregiving and be excellent Do-ers. But the problem is that they may not have any good internal measure of how they are doing (often something emotional within the person) and therefore they look outside for cues as to how they are doing. They may appear insecure about caregiving, etc.

Some parents may be enlisting of the interviewer and open to being comforted still others may be enlisting and prickly - this latter pattern seems less adaptive.

Be careful not to equate expression of affect with resolution - they are not the same thing.

It is critical to remember that we are asking the person for their NARRATION of their experience therefore we are getting a metabolized, highly processed version of the story, the part of that processed version that the parent wants to share with us. Therefore it is highly possible that emotions are and were a very important part of the coping strategy but may not be part of their narration of that strategy - that is they may not share or express feelings in the interview, and may only briefly touch on them in their narration.

Still other parents seem to have converted the experience of the child's Dx into some wonderful story about themselves or the handicapped - One granddad who told a warm and wonderful story about how all handicapped kids are really happy. This is first class denial and an attempt to see people as stereotypes.

SIGNS OF RESOLUTION

Fundamentally, resolution is characterized, following Main and Bowlby, by a re-orientation and re-focus of attention (perceptually, cognitively, emotionally) on present reality, following a period of disorientation and grief. The features of resolution then are a focus on the present, and acceptance of the child's condition and the reality and limitations placed on the child, a forward looking orientation to the child's condition, accurate representations of the child and the experiences of the diagnosis, no effort to bring the past into the room or to bring the interviewer into the emotional worlds of the parent, and some acknowledgement that there has been change since the period of diagnosis. Specific features include the following:

1. Recognition of change since the diagnosis.

Parents will readily acknowledge the difficulty of the diagnostic period and the fact that it may have been disorganizing and traumatic, but they emphasize (to the change question) that their feelings about the diagnosis have changed in some way. They may continue to admit mourning, at times, but note that their baseline emotional response has changed.

2. Assertion of moving on in life.

Parents will note that after a period of mourning and disorganization that they had to move on. "You have to do what you have to do" or "we had to get on with our lives" are statements found commonly in resolved parents. Again, despite admission of trauma, these parents keep it in the past by noting a need to cope with the situation as best as they could and a moving on - many place these experiences in some sort of timeline, with moving on indicating their orientation to the present and future.

3. Suspending the search for a reason.

Almost all parents admit to wanting to know why their child has cp (functional question) or why they have had to parent a child with cp (existential question). Resolved parents will indicate they are no longer involved in the search for the answer to either of these questions, and most often will say "you just accept it" or "you never get and answer so you just have to stop asking."

4. Accurate representation of the child's abilities.

If a discussion of the child's capacities is part of the Rx to Dx interview (as it is for some) the parent will give a description of the child's abilities that appears consistent with observations of the child. The parent may hold high but not unrealistic expectations for the child, or better yet, admit to having hope for high expectations but acknowledge the uncertainty of the outcomes. If the child is very impaired, the parent will give a representation of the child consistent with these impairments.

5. Balanced statements regarding benefits of the experience to the self.

Unlike Unresolved parents who focus on the self, resolved parents may explain that raising a child with special needs has had some benefits (I am a more patient or accepting parent) but will also acknowledge that that has come with some difficulty or that the child's disability is by no means worth the benefit to the parent.

Additional notes related to resolution of the diagnosis

Does the parent express some affection for the child or show some ability to take the child's perspective at some point during the interview? These are parents who appear to have some distance from the child yet the ability to see the child accurately.

Does the parent talk about something in the past, pause, then look away as if to take a moment to relive the past without bringing it into the room (respectful to interviewer) moment and feelings are accessible but do not break into present.

On the question about why? Does the parent allow herself to think odd thoughts (and even share them) but not believe them. This is important because many parents will admit to having some "unresolved looking" thoughts about why they have a child with CP (usually in response to the existential question) and they will share them with the interviewer but will do so in a way that indicates they do not really believe these thoughts.

In our business we may not give anywhere near enough credit to people who focus on doing instead of feeling - sometimes the doing is a real important part of dealing with any loss and getting on with life is really the most adaptive outcome of any grieving process - maybe we should focus on their talking about doing - maybe the absence of talking about doing should also be a flag for us - if you are so focused on feelings then maybe you are not doing much - needs to be a balance between the feeling and the doing. With regard to people who emphasize "doing" as a means of resolving the diagnosis, we are struck with the number of people who are not highly verbal who strongly indicate a sense of resolution without a lot of "meta-processing" of the experience or reporting about feelings. Instead they appear to respond to the child's basic needs for caregiving and readily indicate acceptance of the child and situation.

Notion of reason for problem - that child has a purpose in being but not so specific (to become a doctor) or connected to parent (to shape up my life) - but an openness to possibilities.

One point is that you do not have to go through a devastating grief process, or report devastation, in order to have resolved it.

Some action people (Do-ers) can think about feelings —they just don't. These folks tend to mention feelings easily, may have shadows of feeling cross their faces, but then quickly (and comfortably?) move back to action. Others may have more difficulty thinking about feelings, and not be able easily to mention them.

It may be useful to make a distinction between those who consciously choose not to think about feelings and those whose not thinking about feelings results from an unconscious strategy of keeping from thinking about feelings by staying totally focused on actions.

Classification of Subtypes for
the Reaction to Diagnosis Interview

The primary classifications in the Reaction to Diagnosis Coding System are for Resolved and Unresolved categories and these are described in detail elsewhere in the manual. The classification of subtypes is intended as a further, more detailed and differentiated description of the strategy (strategies) used by the parent to attain the Resolved or Unresolved state. That is, resolution or lack of resolution is viewed as a generic form of coping with the child's diagnosis and the subtype classification is intended to identify specific ways in which the parent deals with the child's disability in his/her mind. The subtype classifications are similar to, but not identical to, the elements of resolution and lack of resolution described in the manual. This is because the elements are viewed as more molecular-level signals of the resolution process and it is assumed that any given parent will demonstrate a range of these elements in the interview. The subtype classifications then are middle-level constructs in terms of generality, between the molar level dichotomous resolved/Unresolved classification, and the molecular-level elements that are commonly present in the interviews.

The person coding the Reaction to Diagnosis Interview will first use the procedures described in the Manual to perform a Resolved/Unresolved classification at the molar level. This will yield a highly reliable and valid description of the parents' state of mind with respect to the diagnosis. The subtype classification follows from the major classification. After making the Resolved/Unresolved classification, the coder then examines the subtype descriptions within the major class and makes a subtype classification based on those descriptors. The subtypes are as follows:

Resolved

Feeling Oriented

Action Oriented

Thinking Oriented

Unresolved

Emotionally Overwhelmed

Angrily Preoccupied

Neutralizing

Depressed/Passive

Cognitive Distortions

Disorganized/confused

Descriptions of Reaction to Diagnosis Subtypes

The subtype descriptions are intended to describe a strategy for dealing with the information that the child has a disability or medical problem. Again, this information usually has to be dealt with at both an emotional level (the parent has feelings about this that we assume are at first unpleasant) and at the cognitive level (in terms of expectations for the child, beliefs about the reason, awareness of the child's problem). Parents may use particular strategies for doing this cognitive and emotional work, and the subtype descriptions are an attempt to capture these strategies. It is true that there are probably as many strategies and combinations of strategies as there are parents: the subtype descriptions are intended to group these in meaningful combinations and reduce the universe of strategies to some meaningful set that can then be validated against specific parental behaviors when interacting with the child.

A. Subtypes of the Resolved classification

A.1. Feeling Oriented

The primary impression of the parent is that they make their feelings very apparent in the interview (NOT ENLISTING). They keep their feelings as their own, do not seek sympathy or nurturance, but clearly refer often to their feelings throughout the interview. They may relive the past within themselves but not make it apparent to the interviewer. Again, the overall impression is that the parent's feelings are exceptionally available to them and they use their easy access to feelings in coping with the diagnosis. They may say that one thing that's gotten them through this is being able to talk about their feelings with friends, or they may say they refer back to the experience. Their memories of the experience of the diagnosis tend to be memories of feelings as well as events.

One mother was virtually transparent in her reporting of her experiences, it is as if the experience and her feelings became immediately available to her in the room, although she kept them private (did not enlist) but shared what she was feeling and thinking about at the time. She frequently reported feelings of grief and needing to grieve; in fact many of these parents recount the need to grieve and the process.

Clarity of the interview is often pronounced.

Feeling subtype may not be clear on how they got resolved, they just are.

This may be a more expressive subtype, these folks are relationship oriented in general.

A.2. Action Oriented

These parents give the general impression of doing - of action and caregiving for the child. They often say "the thing I needed the most was information on what to DO for my child" or "I realized you gotta do what you gotta do" in recounting how their feelings changed or the crisis was over. They acknowledge feelings (which makes them different from the Denying Unresolved type) but they do not linger with them (as the Feeling subtype does)/. It is as if these people feel better by doing something for their kid, the process of grieving becomes one of learning to take care of a child with a disability and incorporate that disability into caregiving routines.

Action-Oriented people can think about feelings, they usually don't choose to. They may mention feelings quickly (in response to the feeling questions) but quickly move to action. There is a very strong competence aspect to these people; of primary importance to them is doing right by their kid.

Some of these parents talk about needing information but its information that helps them DO something for their kid. They are child focused, when information is seen as an important part of the p's resolution process, this subtype is coded when its clear the information helps them do something.

A.3. Thinking Oriented

These parents may have a strong intellectual orientation to their reporting or report a number of beliefs that allow them to "get through the day." It is clear that knowing something about their child and their situation is of primary importance to them, and more importantly, when pressed on questions about how they feel, they respond with beliefs, thoughts, philosophy, etc with their feelings acknowledged somewhere underneath all that. These parents are comfortable with their beliefs and thoughts about the experience (unlike Unresolved parents) and easily recount their experiences. What distinguishes them from the other Resolved subtypes is their emphasis (past and in the present interview) on cognitive processes.

These parents often respond with "well what I think is that...." or "the way I see it is....." basically giving you their beliefs about the situation and its effects. It is important to remember that like the Action Oriented group, these parents CAN acknowledge their feelings, but they do not linger there, they quickly move into discussion of beliefs, information, etc., all of which can be seen in the context of mastery of the situation.

What's key in this classification is the parents reliance on a set of beliefs to help

them get through this experience - these beliefs could be statements like "she's my pride and joy" or "you learn to live with it", or there could be religious beliefs or "my faith has helped me through all this", so that thoughts and beliefs can be "imposed" or brought in from the "outside" of the parent as well as generated from within their own processing of their experience. The coder should NOT confound this classification with high verbal ability or philosophizing.

B. Subtypes of the Unresolved Classification

B.1. Emotionally Overwhelmed

This parent is easily upset by the content of the interview, often breaking into tears when the topic is introduced, or when asked to recall feelings and events. The way they recount their experiences tends to "bring to feeling into the room" and may evoke a very sympathetic reaction in the interviewer, to the point that the interviewer feels pulled to nurture the parent. These parents are living the feelings "like it was yesterday" and have great difficulty maintaining composure during the interview. The primary impression left by these parents is a feeling of wanting to take care of them, or sympathy, that they are "stuck in the past," and that they are still actively in the crisis period of grieving the sadness and pain of the diagnosis.

Primary issue is that the feelings are in the room, the parent is actually grieving during the interview, as if the news was being delivered.

#109 is prototypic

B.2. Angrily Preoccupied

This parent is actively angry in the interview. The anger may be directed at the medical system, the diagnosis, the interview or other topics and may be realistic in origin or unrealistic. What is common in these cases is that anger is thematic - it runs throughout the interview and often the parent gets "wound up" in it in the sense that they cannot stop themselves from expressing it at every occasion in the interview. There is likely to be a sense that the parent wants the interviewer to see it their way - enlisting the interviewer's impressions or feelings to share the parents' perspective. The style of response may include rapid speech, an enlisting, whiny, or questioning tone of voice, angry derogatory remarks. Anger is evident in slips of the tongue, lapses into present tense, failure to mark dialogue as belonging to one or another person when discussing what others' have said, and a tendency for dialogue or responses to run on and on and on, as if the parent cannot stop themselves.

The coder has the impression that the purpose of the parent's story is to express

anger and have the interviewer see things the way they see them. This subtype is "stuck in the past" in the same way the emotionally overwhelmed subtype is, but the predominant feature is "stuck" in the anger emotions associated with grief process.

These parents may "pull in" the interviewer but they are also kind of prickly so the interviewer may not feel very empathic; there may be a sense the parent needs to let out the rage, there may also be the sense that the parent is actively angry that he/she cannot undo what has happened to her and her child.

#s 105 and 114 are prototypic

B.3. Neutralizing

These parents show a predominant strategy of neutralizing the emotion associated with the interview and the events being recalled. The parent may report denial ("I didn't want to believe them"), but unless they actually show denial or neutralization in the interview, they do not fit this category. This subtype is specifically aimed toward those parents whose behavior in the interview (as well as their report of their behavior during the events on the Interview) is avoidant of or neutralizing toward emotion. This can be seen in active avoidance - "I do not or cannot remember" or "I did not feel anything or do not feel anything" and it may be seen in a more sophisticated (and complicated) strategy of neutralizing in which there can be excellent recall for detail but no recall of feelings or demonstration of emotion (negative) in the interview. The prototype for the neutralizing is the woman who recalled the story of her labor and delivery (very preterm) as anchored around how she looked and how she felt good because she had just had her nails done. These can be very sophisticated and verbal people so this pattern may be fairly subtle in its presentation. The primary feature is a sense that the parent does not perceive or report negative emotion, especially in themselves, associated with the diagnosis or events around it. They appear cut off from the experience of the diagnosis.

Important to note that neutralizing is coded when it is the primary strategy even if it is an unsuccessful strategy and affect leaks through on occasion - these parents may recall feelings and detail that's safe to recall and avoid the rest.

#215 is prototypic

B.4. Depressed/Passive Resignation

The presentation of these parents in the RxDx Interview is the key to this code.

They appear sad, listless, very passive, requiring lots of probes and effort on the part of the interviewer. Their report is minimal. They appear depressed, or their affect may be flat and accompanied by a very passive style of interaction. The content of their interviews may also be depressed, such as the mom who reported feeling hopeless and depressed. These parents appear stuck in the sadness of the experience or overwhelmed at the prospect of the care the child needs, etc, with very little hope for the future.

#211 is prototypic for depression

B.5. Cognitive Distortions

These are parents who have distorted the events or feelings or information available to them about the child and the diagnosis. This can take many forms and may involve expectations that child will become a neurosurgeon (as reported) to give an extreme example, but generally they show a distortion of information about the child or an unbalanced perception regarding the benefits of the experience. For example, one mother reported how wonderful her very disabled child was and what he brought out in other people, and did this repeatedly in talking about how her feelings have changed and as an answer to the why question. She did not acknowledge any pain or negative consequences (for her or her child) of this child's disabilities. This unbalanced perception is distorted in the sense that their parent appears to have a very selective filter for information and either does not allow certain information to be processed, or distorts some and ignores other.

These distortions may or may not be accompanied by nonverbal expressions (wringing of hands, anxious laughter) that suggest the parent is not altogether comfortable with this resolution of the experience.

The primary issue here is lack of balanced perceptions - beliefs have an all or none quality, there are apparent internal contradictions in beliefs that are not acknowledged - parts of the belief system are separated from others. There is a disproportionate emphasis on one facet of experience at the expense of not perceiving other facets. There may also be distortion at the level of the "whole" in the sense that the parent has odd views about their entire experience/meaning of the DX.

#219 is prototypic; #s 111 and 233 show strong features of this subtype.

B.6. Disorganized/Confused

This subtype is marked by incoherence in the content of the story (at times it is not logical or does not make sense) and by appearance of confusion and

disorganization in the presentation of the story. The parent may ramble, lose their train of thought and need to be re-oriented by the interviewer, they pursue tangents in the story and do not present a concise or coherent package, and their story may be contradictory or even have no discernible point or conclusion. Their disorganization is evident in their presentation, one mom had a furrowed brow, looked quizzically at the interviewer, etc. She organized her story around the family going for a pizza. Parents may also show oscillating perceptions in which they describe the experience using one term and then immediately describe it using a contradictory term, or take back their original description as if they cannot seize upon a description and oscillate between polarized perceptions. One mom described her feelings on hearing the Dx as "relieved/concerned/relieved/concerned." A sing-song tone of voice may accompany these reports of oscillation.

There may be evidence that the search for reason is "on" and a sense that there has not been a point around which the parents' experiences and views of the DX have become organized. Therefore you see oscillations, attempts to seize upon a point/meaning, and confusion. There may be a sense of polarized impressions (by parent) and that it's difficult for the parent to "get on top of" this experience psychologically.

#226 is prototypic

Reaction to Diagnosis Codes for TRAINING TAPE

<u>Family ID #</u>	<u>Main Code</u>	<u>Subtype Code</u>
103	resolved	thinking
104	resolved	action
105	unresolved	angry
106	resolved	feeling
109	unresolved	emotionally overwhelmed
124	unresolved	neutralizing
208 212	unresolved	emotionally overwhelmed
212 208	resolved	thinking
215	unresolved	neutralizing
222	unresolved	disorganized-confused
111	unresolved	cognitive distortions
211	unresolved	depressed