Abuse and Down’s syndrome:  
A Case Study of a Dying Man and His Family

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James, who goes by Jim, is a 61 year old father of three. His two eldest children, Lisa and Michelle (ages 34 and 36), are full-grown and married, living out of state. They are from Jim’s first marriage. His youngest child, Ben, is 21 and lives at home. This child is the result of an affair Jim had with a woman named Randy. Ben also happens to have Down syndrome and Asperger’s. Currently, Jim is not on good terms with his daughters and has full custody of his son.

Over the last 20 years or so, Jim has suffered from multiple bouts of stomach, skin, lung, kidney, and prostate cancer. Before his sickness started increasing, he had run an electrical contracting company. When he became too ill to work, his company suffered and he began to experience financial instability. His parents, Jim Sr. (age 82) and Marie (age 78) have provided their son a home and regularly help him with rent and other necessary payments.

Right now, Jim’s sickness has increased dramatically and his family has decided to put him in hospice care. With Jim off his medications and on pain medications prescribed by the hospice workers, he has become very energetic about finishing up loose ends before he dies. In the last few weeks he has come forward about sexual abuse he suffered as a child in Catholic School and wants to sue the Church for not protecting him. Jim plans to give the money earned from the lawsuit to fund the special needs of his son, Ben. He also has given custody of Ben to his ex-wife, Kelly. His youngest brother, David has been given power of attorney and is aware of the situation, but very distraught; as is the rest of the family. Another thing to note is that none of the family members agree with Kelly having custody of Ben.

As a case manager, for this particular situation (and for the purpose of this paper) I would focus on one key area: family support services. This is a complicated case with a lot of circumstances, but from the scenario above, it does not seem as if Jim’s relatives’ needs are being addressed. These needs include grief counseling over his imminent death and to develop coping skills (or even to treat trauma) over the knowledge of his past sexual abuse. Also, as part of family support services, the situation of who gets custody of Ben can be taken care of.

Before I can determine what intervention models to use to help the family, I must understand the populations involved. Jim, himself, makes up two populations. That of late adulthood, or Erickson’s Death and Dying stage, and the population of male, child sexual abuse survivors. Even though Jim’s family, who I am working with, may not fit into these two categories, they are inadvertently affected by the population. I am only going to focus on the association with male sex abuse survivors. 1 in 6 males are sexually abused by age 16. The sexual abuse of male children can lead to a variety of problems and suffering. First, being that the experience is both painful and can potentially damage the development of that child thereafter. Second, whether and to what extent child abuse and neglect (or other painful experiences) have negative effects depends on a variety of factors—related to the abuse itself, but also to relationships, in which the abuse and the child's responses occur. Finally, though suffering has and might continue to occur, it is important to note that the abuse might not necessarily be the cause of future struggles and issues and in no way “dooms” the child to a life of suffering (Hooper, 2012). However, even with that understanding, the potential long-term effects on male sex abuse survivors is a long list. The emotional effects might include anger, fear, homosexuality issues, helplessness, isolation and alienation, legitimacy, loss, masculinity issues, negative childhood peer relations, negative schemas about people, negative schemas about self, problems with sexuality, self-blame and guilt, and shame and humiliation. From those emotional effects, behavior is also affected. This includes anxiety, depression, dissociation, hostility and anger, impaired relationships, low self-esteem, sexual dysfunction, sleep disturbance, and suicidal ideas and behavior (Lisak, 1994).

The other population in this case scenario in that of a young adult with Down Syndrome. According to the National Down Syndrome Society (NDSS), One in every 691 babies in the United States is born with Down syndrome, making Down syndrome the most common genetic condition. As of right now, approximately 400,000 Americans have Down syndrome and about 6,000 babies with Down syndrome are born in the United States each year. Individuals with Down syndrome are slowly gaining more acceptance and inclusion into society and community organizations, such as school, health care systems, work forces, and social and recreational activities. The effects of having Down syndrome on a person are unique to each individual, but most share a common cognitive delay that ranges from mild to moderate (NDSS, 2012). Ben is part of the more uncommon population of individuals living with Down syndrome. He also has Asperger’s syndrome, which impairs his social skills. Along with that, he is also living at home still instead of a group home at the age of 21 (when transition into such a place usually takes place).

Intervention models I would prefer to use would help the family deal with addressing the turmoil caused by the abuse and help find the best placement for Ben (and use of the money *for* Ben once the lawsuit goes through). Overall, I would use an responsibility-based model for myself. A responsibility-based model is focused on “the transition of care from human service professionals to nonprofessional” (Woodside, 2006). This model focuses on the idea that work still continues after services have been “officially” terminated. Jim is about to die, thus he would no longer be a client. However, he is leaving behind baggage and a custody battle, thus services will still be necessary for his surviving relatives.

The best model related to addressing turmoil over Jim’s history of sexual abuse would, in my opinion, be a crisis-intervention model—specifically one dealing with rape. Not because the abuse it currently going on, but because there are steps in this model that deal specifically with helping the family cope with knowledge. Especially with a topic such as “male rape”, which tends to be taboo in our culture, coping skills and communication need to be addressed and implemented. Part of the crisis-intervention model is the use of hotlines. These are places a person can call—places like 342-RAPE—that can work with an guide both the victim and their families through recent, past, or suspected sexual abuse and assault cases. Another piece to crisis-intervention is getting the individual(s) involved with an advocacy group. For Jim’s family, I would suggest, MaleSurvivor or The Good Men Project. Both of these organizations work with the male victim and their families on coming to terms with what occurred, dispelling myths about the subject, and rebuilding foundations of strength and hope where there might be fear and turmoil.

In regards to Ben’s situation, I would suggest the strengths-based model. Though the various relatives in the family might have different perspectives on what are Ben’s best interests, in the end, he deserves to put himself in a place of comfort—regardless of overall efficiency. According to the University of Kansas’ School of Social Welfare, “the Strengths Model is a recovery-oriented approach to working with people with psychiatric disabilities.  The Strengths Model is both a philosophy of practice and a set of tools designed to help people set meaning and important life goals and draw upon both personal and environmental strengths to achieve them” (University of Kansas, 2012). Though, once the lawsuit comes through, Kelly might use the money in a way that does not benefit Ben, if he chooses to life with her that is his choice. As a case manager, I cannot get sucked into the family drama. All I can do is empower Ben by helping him make his own decisions.

While the models I just reviewed may be particularly effective in this family’s circumstances, there are other models that may not work so well. These models include a family intervention model, any models pertaining to drug and alcohol intervention, and (though I did include it in the former group) a crisis intervention model. Family intervention models wouldn’t work because they deal with issues within the home that relate to abuse and neglect. Ben is not being neglected, his relatives are simply in disagreement about where his future placement should be. Models that deal with drug and alcohol intervention and prevention wouldn’t be effective at the current point and time. There is a chance that such models might be needed later on (say a relative becomes too stricken over realization about the abuse and turns to substance abuse), but there is no need to consider them just yet. The same can be said for suicide prevention models. Finally, certain components of the crisis intervention model deal with the victim of abuse. As Jim is dying, those components are not going to be effective for very long.

Throughout all of this, there are many ethical concerns that may or may not arise while working with a male rape survivor and a young adult with Down’s syndrome. According to Haverkamp (1993), in regards to working with a male rape survivor, informed consent and disclosure, mandated reporting of abuse (if the abuser still lives), and the therapeutic treatment of abuse all have ethical considerations. In regards to informed consent and disclosure, talking about abuse can open old and new wounds. Though each individual involved is allowed autonomy and is given the privacy of informed consent, disclosure occurs when suspicions about abuse and/or threats to someone’s life are brought up. This can breach the individual(s)’s trust of the case manager and could tamper with the effectiveness of the intervention models and strategies being utilized. These concerns are the same with the ethicality of mandated reporting. Therapeutic treatment of the abuse needs to be considered for its theoretical approaches. Not all work for every client—some might even be more damaging dependent upon the circumstances. Also, there is the chance that a case manager is not adequately trained in that area of therapy, thereby risking legal and ethical complications (Haverkamp, 1993).

Ethical concerns in regards to working with young adults who have Down’s syndrome (or any other intellectual disability) include informed consent and disclosure, therapeutic treatment, and mandated reporting, as well. However, there are slight differences. Because there are varying levels of cognitive underdevelopment in individuals with such a syndrome, informed consent and disclosure can become muddled as the individual might say (or not say) certain things that raise suspicion and disclosure of such conversations might occur to someone that can interpret what the individual has stated, thereby compromising the trust between the client, the case worker, and any other individual involved. Therapeutic treatment can include medication, counseling, physical therapy, and other methods. There are ethical concerns about what extent a professional should treat an individual with an intellectual disability. Because Down’s syndrome is known for causing a long list of health issues, there has been a movement to inject the individuals who have it with a “normal person steroid.” At least, that is how I view it, as I have experienced being faced with this decision for my own cousin who has Down’s syndrome. Finally, there is the ethical concern of mandated reporting. Even if it is at the risk of separating families or causing harm to someone, suspicion of abuse must be reported. 85% of people with Down’s syndrome are abused in some form, whether it be physical, mental, or sexually. There is a serious problem with that and it *must* be addressed (Brown, 1996).

If Jim and his family were from Whatcom County, they’d have several services available to them. For individuals like Jim, who have survived rape and are male, there are no physical, secular entities in Whatcom County for them to turn to. However, there are many church group, such as those given by the Catholic Church—as they have had extensive history on this subject—that provide services to such victims. For Ben, however, there are more opportunities. Whatcom County has many programs for individuals with intellectual disabilities. One that specifically relates to Down syndrome is called The Arc. This group has a program called Down syndrome Outreach. The group is made up of people with, and without, Down syndrome, who advocate for equal treatment amongst all developmental abilities. They put on many events, including the Buddy Walk, which is a Walk through Fairhaven promoting equality (The Arc, 2012).

The laws and policies in place around these two populations are not too restrictive. I would say those with intellectual disabilities have more restrictions simply because of prejudice and stereotypes about the abilities of that population. Ben will have a significantly more difficult time finding a job and gaining independence than a boy his age without Down’s syndrome. However, ADA and Section 504 are two comprehensive laws that exist to protect such individuals. Ben has a lot of legal support.

To conclude, there are many ways a case manager can approach a situation. Sometimes we can do a lot for the group involved. Other times we might only be able to do something small (to us) for one individual. For this particular case, I didn’t even focus so much on the client. Jim was nearing his death. What he needed was for the family he left behind to be in a healthy state of mind and situation. That is why I focused on them in regards to intervention models. Nothing is set in stone; the possibilities are endless; but, we can still do something for every case that lands on our desk. It’s up to us to make that “something” happen.

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