Case Study Report
Student with PKU and Emotional Distress

Natalie Green
EDUC 5501.01
June 23, 2010
Overview

Ben is a seven-year-old student in a Grade 1 class with average academic success. He is capable of meeting all curriculum outcomes and does so regularly. Ben is likely capable of excelling in many areas of the curriculum, but has difficulties in the areas of focus, attention, concentration, organization and memory. When he is interested in what he is doing, attends to a lesson to hear the directions, and receives some prompts from the teacher or his classmates during the task, he completes work of a high quality. His reading, writing and spelling skills are strong, however, he can stray from his task if it does not peak his interest. His mathematics skills are not as strong as his skills in Language Arts, but he is keeping up with his classmates. As he progresses through school, his difficulties may prove more of an issue. His interest areas include, but are not limited to, Michael Jackson, some sports, animals – especially dogs, firefighters (his father’s profession), and television shows that are also games (i.e. Pokemon).

Ben is a very social boy who is liked by his peers. Ben relies on others’ attention for high self-esteem, and this can be an issue. When excited, he can behave inappropriately, especially towards adults in terms of what the classroom teacher calls “manners” – respectful behaviour. In disagreements with peers or when chided by an adult, Ben can be very emotional which presents as either closing himself off or being disrespectful. He is a physically fit boy with Phenylketonuria (PKU), which is a dietary condition explained below. Physically, Ben’s fine and gross motor skills, visual-motor coordination, speech, hearing and mobility are average for a child his age. Emotionally, Ben can be unstable because he misses his dad. His mother and father are married, and his father is working in Alberta, so Ben only sees him every few months. Ben also has a little sister, and a grandmother who lives nearby and runs the EXCEL program at his school. Missing his father may explain some of Ben’s emotional outbursts in school, so he may have a form of emotional distress which is explained below.
PKU and emotional distress

PKU (Phenylketonuria) is “an inherited error of metabolism in which the individual cannot metabolize (or use) the essential amino acid, phenylalanine” (Bellenir, 1996, p. 63) which is found in protein foods. Detecting the condition at birth is vital because if the condition is not detected and immediately treated, normal brain development is prevented (Bellenir, 1996). Fortunately, detecting PKU at birth has been done with routine blood tests since 1991 (Bellenir, 1996). The PKU diet consists of restricted amounts of phenylalanine (phe) which is found in protein foods such as meat, dairy products, fruits and vegetables (Bellenir, 1996). The parents of the child with PKU and, as (s)he ages, the child with PKU, monitors intake of phe foods using a point system. To compensate for the lack of protein, a liquid beverage or formula is taken which contains a special protein source or medical food taken twice a day (Bellenir, 1996). Not remaining on the strict diet prescribed for individuals with PKU has severe negative impacts such as behaviour problems, distractibility and/or ADHD (attention deficit disorder), low IQ, depression, phobias, ODD (oppositional defiance disorder) and social incompetence (Brumm, Bilder & Waisbren, 2010). Ben has remained on his diet since he was diagnosed and therefore does not have any of these challenges, but may develop them if at any point in his life he discontinues or modifies his diet. Even if an individual with PKU remains on their diet, it may impact a student in terms of social and emotional behaviour, as well as cognition and academic success.

According to Brumm, Bilder and Waisbren (2010), even if an individual with PKU remains on their diet, they will likely display inattention and distractibility in childhood and depression and anxiety in adulthood. These factors contribute to Ben’s emotions and self-esteem as a student, as well as his social capabilities. In terms of academic success, VanZutphen et al. found that individuals who follow the strict PKU diet displayed “difficulties in visual – spatial and perceptual – motor skills and in frontal [lobe] skills (planning, working memory, and inhibition). Abstract reasoning, problem solving, reaction time, speed of mental processing, and sustained attention ... appear to be consistently deficient” (2007,
p. 13). Brumm and Grant found similar findings and added deficits in “conceptual reasoning, selective ... attention, inhibitory control, and organizational strategy” (2010). With all these factors working against him, it is a wonder Ben is performing as well as he is in school. However, Ben may not have all of these difficulties, or may be affected by them at different levels at different times. Bellenir provides the following wonderful suggestion for elementary school teachers of students with PKU: “The child with PKU needs to be treated as any normal child, with strengths and weaknesses, likes and dislikes, and a learning style unrelated to the PKU condition” (1996, p. 58).

Emotional distress is a generalized term that includes, but is not limited to, various forms of anxiety such as social anxiety, generalized anxiety, separation anxiety, social phobias and specific fears or phobias. To my knowledge, Ben is not diagnosed with any of these, but I believe his emotions are impacted by his situation. As explained above, Ben’s father lives in Alberta to work, and Ben sees him only once every few months. For a few weeks after he sees his father, Ben is happier, more focused on school work, more skilled at social interactions and exhibits less inappropriate behaviour than is usual for him. Ben’s situation may be compared to that of a family with divorced or separated parents, which research has shown might produce lower academic self-concept and personality problems for the children involved (Smith, 1990).

**Practicum context**

Ben attends a small elementary school of just over 200 students (School Finder) situated in a community of about 30,000 people (Community Website). Most students, including Ben, walk to school, but there are two buses that transport some students to and from school. There are 12 other elementary schools in Ben’s community (Community Website). Ben’s school was built in 1974 (School Finder) and therefore has some restrictions in terms of universal design and modern technology. Ben is in the only Grade 1 class in his school; there is also a Grades 1 and 2 combined class. His teacher and many of the teachers in the school have been educators for at least 20 years. His school has a resource
room with one resource teacher, a learning center with one learning center teacher and two EPAs (Educational Programming Assistant), one reading recovery teacher, one literacy coordinator, a part-time speech therapist and a part-time school psychologist. There is a library with a part-time librarian, and a physical education and a music teacher who are shared with a nearby school. There is no lunch room but there are two regular lunch monitors on Ben’s floor of the building. There is an EXCEL program in place for before and after school hours. There is one computer lab in the building which is shared by all classes and two computers in Ben’s classroom.

Currently, Ben does not visit the resource room or learning center. Two of his classmates go to the resource room three mornings a week, and four of his classmates attend reading recovery. His grandmother runs the EXCEL program but he does not attend. As Brumm, Bilder and Waisbren state, “dietary therapy [for children with PKU] is highly restrictive, necessitates close monitoring by parents, and highlights how children with PKU differ from [their] peers” (2010), so lunch time is especially important for Ben to feel included. Ben stays for lunch and the two lunch monitors on his floor know of his PKU. The classroom teacher has set a classroom rule of not sharing food to ensure Ben does not feel tempted to stray from what his mother has packed him for lunch, and to ensure he does not feel different from his peers for not being allowed to trade food. The classroom teacher has also placed Ben on her own behaviour program, along with some other boys in the class. This program involves extra attention and reminders of how to behave, as well as another explanation of a task after students have returned to their seats. The boys are rewarded for good behaviour with computer time or a small toy and punished for bad behaviour by being kept indoors for part of recess. This program is helping Ben to succeed, but when an aspect of it is missed or forgotten, Ben has been known to stray back to disruptive or inappropriate behaviour.
Impact of practicum context on the student

Many aspects of the practicum context are working well for Ben. The community feeling of the small school helps Ben feel like he belongs and the lack of a lunch room ensures Ben does not have to stand out as different from his peers. By eating a lunch his mother packs for him, and having the rule in place not to share food, Ben’s lunch experience is just like that of his peers. Some of his classmates get a “hot lunch order” on some days, but not all students do this at all times, so the fact that Ben never eats anything other than from home does not make him stand out. The classroom teacher and lunch monitors are aware of Ben’s PKU, so during recess, lunch and special party occasions that involve food, the no sharing rule is upheld. For party occasions, the classroom teacher often attempts to provide games or toys to the students instead of candy, or, if food is present, Ben’s mom attends the party along with other parents as volunteers and monitors what Ben eats. In these situations, every attempt is made to make Ben’s choice of food casual. Often, his mother quietly mentions to the other parent volunteers and the teacher what and how much of the available food should be offered to her son so that he does not have to worry about whether he can eat it and his mother does not have to hover over his shoulder.

Outside of diet, another aspect of the practicum context that is working well for Ben is the seating plan. While I was there for practicum, I randomly chose a partner for Ben to do an activity with and found that they worked phenomenally well together. I praised them and Ben was a model student for the rest of the activity. The next day, I moved the desks so that Ben was sitting next to this girl who had produced such great effects in him. During the rest of my placement, Ben was better able to stay on task and complete his seat work with the guidance and presence of this girl. Her impact was only seen while they were sitting next to each other at their desks, and I did not enforce them sitting near each other at other times, so I do not know if her effects will continue to help Ben, or if she may “wear off” after time.
Some aspects of the practicum context are not working well for Ben. He is not receiving any special support for his emotional distress or his PKU. The behaviour program his classroom teacher has placed him on is working, but her behaviour program is designed to be slowly reduced and whenever aspects of the program do not take place, Ben struggles. A more permanent structure must be put in place for Ben. Her reward and punishment system in her behaviour plan is counter-productive to Ben’s needs. By being kept indoors, Ben cannot “run off” his energy and then has extra trouble focusing after recess. Computer time is a great reward and motivator for Ben, but computer time almost only happens after a period of good behaviour rather than on a more regular basis as could benefit him as outlined below in assistive technology. Currently, Ben is taking his formula before and after school to avoid the stigma of drinking something very different from the other students, the bad smell of the formula, and the bad breath it gives him. While not taking his formula at school is an asset to not feeling estranged, not taking his formula at lunch time goes against the suggestions of his doctors. He should be taking his formula at certain intervals, and the entire school day is a longer duration than is recommended. Not drinking his formula affects Ben’s protein levels and therefore his behaviour and brain function (VanZutphen et al., 2007; Brumm & Grant, 2010).

**Mitigating the difficulties**

To mitigate the difficulties of the classroom setting, Ben could be placed on a more permanent behaviour program which could include self-directed reminders he can refer to such as pictures he has drawn of himself behaving correctly in particular situations. Ben’s formula is one of the biggest difficulties of the classroom setting and is not easily mitigated. If he is comfortable, he could go to the office or resource room to drink his formula at the beginning of lunch when the other children are washing their hands. He would not be drinking something different and foul smelling in the presence of his peers, and would also not be missing out on any lunch or class time because by the time he finished drinking his formula, he would be returning to the classroom at the same time as his peers who were in
the washroom. In his classroom this year, the students often go to the washroom in shifts a few minutes before the bell rings so that the washroom is not full of students at any one time. Because of this, Ben would not have to leave class early or return late if he goes elsewhere to drink his formula. However, not all classes run the pre-lunch hand-wash in this manner, and so a new system would have to be set in place with his new classroom teacher each year. In addition to the option of going elsewhere to drink his formula, Ben could bring a toothbrush and toothpaste to school to help eliminate the smell of the formula from his breath. Another option would be simply talking to the students in the class about different dietary needs and encouraging Ben to drink his formula with his lunch and allowing him to brush his teeth afterward. When he moves on to junior and senior high school where there are lunch rooms, further considerations will need to be made.

Adaptations recommended for the student

Ben does not require an IPP, but some adaptations may benefit him. Some adaptations may include some form of counselling from either the part-time school psychologist or the resource teacher to support him in dealing with his emotions. These personnel may also suggest ideas to the classroom teacher to help her support Ben when he misses his dad or when he needs to control his emotions. Various opportunities to healthily express his feelings may benefit Ben, including keeping a journal, drawing or colouring what he feels, or role-playing healthy interactions with his peers.

To help Ben with his focus and attention, he could be given extra reminders of what is expected of him which could include a visual task outline as a handout, extra verbal direction, a visual and/or written reminder of general classroom behaviour posted on his desk or on the wall nearby, or some sort of secret bodily code understood between him and the classroom teacher to get back on track such as touching her nose or tapping his desk. Because Ben performs best on tasks he is interested in doing, anything to make the task interesting will help Ben thrive. Many low and medium tech assistive technologies are available that may help Ben remain interested in his work.
Assistive technology recommended for the student

Some assistive technologies that may benefit Ben are varieties of pencils, pens, erasers and grippers to keep writing interesting; highlighters, pocket folders, timers, graphic organizers or a planner to help keep him organized; graph paper, an abacus and math manipulatives to make math a hands-on activity; and books on tape or interactive books (such as Leapfrog® products) to keep reading interesting (Province of Nova Scotia). Computer access may also benefit Ben. He is very interested in the computer and always looks forward to computer time, so finding a way to have him do some his work on the computer may help him perform better. A computer program that may benefit Ben is Social Skills Builder which allows students to view and participate in virtual social interactions that are handled appropriately and inappropriately.

Plan for differentiating instruction and assessment

To support Ben in the classroom, I would differentiate my instruction to meet his needs. Some ways I would do this could include group work for Ben to practice social interaction and further develop his speaking and listening skills. I would also use a learning contract for Ben and his teachers to discuss expectations for class work. This tool would encourage Ben to take responsibility for his own learning and behaviour. To help Ben release energy and keep on task I would ensure movement is a part of my instructional time. This may include learning through role-play or experiments or simply asking Ben to help hand out materials, allowing him to fidget with a small ball, or allowing him to stand while others sit. Visual cues could accompany my verbal and/or written directions and these directions could remain in plain sight to refer to while Ben and his classmates complete their task.

To support Ben’s needs during assessment, I could differentiate my assessment tools in a few ways. I could allow students a choice of representing their knowledge orally, in writing, with visuals, through actions or role-play, on the computer with text and/or images, or a combination of these where the curriculum allows. I expect Ben will represent his knowledge best through actions, pictures, with the
computer or orally, especially for subjects he has some difficulty with such as mathematics. Through oral presentation, Ben could also present his knowledge to the class rather than a one-on-one conversation with the teacher. Doing so would boost his self-esteem as well as promote positive social behaviour such as turn taking and respect for the speaker. One-on-one conversations with the teacher would allow Ben to practice appropriate conversation techniques with an adult, and conversations with a peer would allow practice of appropriate conversation techniques in that setting. I would also provide an outline or reminder system for Ben to help him keep on task so he can complete his work to the best of his ability.

**Universal Design principles that may benefit student and classmates**

A universal design principle that may benefit Ben and his classmates could be a designated place in the classroom for quiet reflection. This space would be for students to relax and calm themselves if they are feeling stressed or need to cool down before dealing with a social interaction or whenever they feel upset. This space could include comfortable cushions, some books and/or a CD player with headphones and soothing music. Other universal design principles that may benefit Ben and his classmates are bright appropriate (non fluorescent) lighting, an elevator to compliment the many stairs in the school, meaningful pictures or symbols as well as text labels around the classroom and in written assignments and handouts, non-white paper handouts to reduce contrast and eye-strain, and closed captioning on all videos shown to the class. Ben does not necessarily need all of these things, but most of them are easily obtained and may be useful to Ben or his classmates in the future.

**Conclusion**

Ben is a very smart and charming boy who can and should achieve great success in school and life. To thrive in a school environment, Ben does not need an IPP but would greatly benefit from adaptations in instruction and assessment, extra emotional support, some assistive technology, and the implementation of universal design principles. As he gets older and progresses through school,
attention should be paid to Ben monitoring his own PKU, dealing with a lunch room or cafeteria when he moves to a school with one, his emotional health (Brumm, Bilder & Waisbren, 2010), organizational and attention strategies appropriate to his age and need, and extra supports in mathematics should he begin to have difficulties as studies predict in students with PKU (Bellenir, 1996).
References


School Finder, *Halifax Regional School Board*, retrieved from:
