Privileging insider-knowledges in the world of autism

Courtney Olinger

Courtney Olinger is a Registered Marriage and Family Therapy Intern with the Board of Behavioral Services in California, USA, who specialises working with families that involve a member diagnosed with an autism spectrum disorder (ASD) and has devoted her practices to integrating narrative theory, community work, and social justice. Courtney can be contacted: Re Spectrum Community c/o Courtney Olinger, 1020 Thomas Ave, San Diego, CA 92109, USA. Email: colinger@respectrum.org

Diagnoses of autism spectrum disorders (ASD) continue to rise. The Centers for Disease Control and Prevention (CDC) of the United States of America suggested in 2007 that 1 in 150 eight-year-olds in the US has autism. In 2009 the CDC prevalence rose to 1 in 110. With the rising number of diagnoses, more families are impacted. Unfortunately, discourses surrounding ASD often present limited views and ways of working with these families. Using narrative practices, insider-knowledges can be privileged and guide professionals. This article presents ways that service providers can incorporate outsider-witnessing to elevate parents to 'expert' status, involve parents' voices, and promote agency. It also includes a collective document of parents' insider-knowledges which can be circulated to inform professionals and parents about the experiences of autism.

Keywords: autism, autism spectrum disorders (ASD), outsider-witnessing, agency, insider-knowledge, narrative therapy

INTRODUCTION

Working with children diagnosed with autism since 2001 has privileged me to a wide range of knowledges about 'autism'. These knowledges have informed my work and the ways in which I interact with those I am hoping to help. According to the Centers for Disease Control and Prevention of the United States,

> *Autism is one of a group of disorders known as autism spectrum disorders (ASDs). ASDs are developmental disabilities that cause substantial impairments in social interaction and communication and the presence of unusual behaviours and interests. Many people with ASDs also have unusual ways of learning, paying attention, and reacting to different sensations. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. An ASD begins before the age of 3 and lasts throughout a person's life. ASDs include autistic disorder, pervasive developmental disorder – not otherwise specified (including atypical autism), and Asperger syndrome.* (Centers for Disease Control and Prevention, 2007)

I will refer to autism or ASD to encompass all labels that fit among those recognised as autism spectrum disorder according to the *Diagnostic and statistical manual, fourth edition* (DSM-IV; American Psychiatric Association, 1994) and the World Health Organization's (WHO) classification system (ICD-10; WHO, 2009).

Through my professional and academic ventures, I have learned about behavioural, medical, nutritional, environmental, and sensory theories about ASD. At the same time, as a person immersed in the autism world alongside the affected children and families, I have stumbled upon 'insider-knowledges' (Kemmis & McTaggert, 2008; White, 2007) which reside outside of the professional realm. Consequently, I have gained perspectives that I highly value as I have come to know families and children who often view autism differently from many professionals. I have witnessed the ways these perspectives have allowed many to transcend limitations that often come along with a diagnosis (Avdi, 2005). Many have been able to escape the confines of social discourse around autism that have gained expert stature in the United States and around the world. Yet, the skills and actions that these families utilise in order to do so are often overlooked or overshadowed by the presence of a professional service.

Working with those living with autism has led me to believe that there is a great need for focus on the entire family. Unfortunately, most services target the individual diagnosed with an ASD and do not account for the effects that ASD can have on family members. I do not mean to suggest that focus on the child is not warranted. Behavioural methods that focus on the individual are useful for teaching children affected by autism and I have often seen a great deal of progress with these children in terms of their learning and development. Yet, I have often wondered what drives the 'behavioural goals' that we (the professionals) determine for these children and how much our services truly assist these children and families to interact in a world that frowns upon differences. Does it make sense that we train children to act 'normally' or are we just perpetuating a greater lack of acceptance for difference?

My introduction to narrative practices led me to question some of the dominant ideas that surround autism. I began to consider the way that autism is constructed because a central component of narrative challenges the notion that problems reside in the 'core' of a person. Rather, problems, identity, and meaning are always being created in the context of one's relationships and social structure (Sween, 1998). Additionally, narrative's focus on the way that language and discourse contribute to meaning enlivened a curiosity about the ways that dominant discourses contributed to the problems that these families faced. Language may be the mode by which meaning is created, but discourse includes the ways in which social and political power influences what is and is not said in certain contexts and who can and cannot say it (Foucault, 1980; Law & Madigan, 1998). Informed by narrative theory, I now consider the ways that discourse shapes one's identity and I seek to deconstruct dominant ideas that can often contribute to problematic representations of a person. As such, my focus turned to centring 'local' or 'insider-knowledges' (White, 2007). I began to observe more closely and listen for the knowledges that the families I worked with had about autism and their lives. My original intention was simply to notice and learn about the knowledges that fall outside the professional realm. Quickly, I recognised how much these insider-knowledges around autism are a largely untapped resource. I was excited but also saddened as I also recognised how much this insider-knowledge does not receive the same status as professional knowledge.

I have taken several steps to privilege insider-knowledge in my work with these families. The following two examples stemmed from outsider-witnessing. With outsider-witnessing, clients are able to tell their story to an audience (outsider witnesses). The role of the audience is not to give advice, fix the problem, criticise, analyse, make judgement, or even 'cheer on' the client. White (2007) explains 'outsider witnesses engage one another in conversations about the expressions of the telling they were drawn to, about the images that the expressions evoked, about the personal experiences that resonated with these expressions, and about their sense of how their lives have been touched by these expressions' (pp. 165–166). They are instructed to pay close attention to the parts of the client's story that catch their attention. After the client tells his/her story, the audience speak among themselves while the client listens. They discuss what pieces they were drawn to from the client's story. They are encouraged to tell ways it may have brought them back to a memory of their own lives. Connecting their reflection to their own experiences is meant to provide a sense of shared experience and they are told to frame such reflections in a way that keeps the client at the centre of their reflection and does not put the outsider witness in the middle. After outsider witness reflections are shared, the client has an opportunity to respond if he/she desires (White, 2007).

The following examples were my attempts at creative spin-offs that would best fit the population I work with and the context of my work.

CREATING GREATER COLLABORATION IN DEVELOPING A PLAY GROUP

I run a play group for children with autism, ages three to seven, which combines children diagnosed with an autism spectrum disorder (ASD) and 'neuro-typically' developing children. As part of the program, parents observe sessions from behind a one-way mirror and attend parent meetings to discuss goals, curriculum, and progress. I had always envisioned that parents would be involved in developing each group, would act as collaborators, and that parent meetings would provide a forum for parents to share knowledges and skills. Using the outsider-witnessing format, I was able to privilege insider-knowledge, build in greater collaboration, and create a context in which parents not only shared knowledges with one another but also with the therapists running the groups.

The particular group I will reference consisted of three clients (all boys, age four, diagnosed with autism), and two peer players (ages four and five). Each group was run by two therapists and all parents for this particular group attended every session (sometimes observing from a one-way mirror and sometimes attending meetings). All three boys were new to the group. After the first two sessions, all parents had a great deal of feedback to give about what would work for their children. Sometimes, such direct feedback is often experienced and talked about among professionals and leads to labels such as 'difficult parents', 'burdensome' and 'interfering with treatment'. However, my view of them as insiders harbouring highly untapped resources led me to search for a way to privilege their voice.

I proposed a new format for the next session and gave the parents the following letter:

> *Dear Play Group Parents,*
>
> *I have received some feedback that has been extremely helpful. As a result of this feedback and my desire to truly make this a collaborative team approach, I ask that we try something new that I am hopeful will provide you (as parents and experts on your child) with a way to have your voice heard. It is my desire to bridge the gap that is so often present between interventions and the families that receive them. As a clinician, I am informed by a great deal of research, literature, and practice; yet, I have an understanding that this 'knowledge' only*

goes so far. In my attempt to best serve each individual child and the families involved I encourage participation by any and all family members.

Today, I ask you to observe with a specific purpose in mind. We will end 40 minutes early to invite you in the room for a Reflecting Team. The Reflecting Team is a practice in the therapeutic world that holds as its premise the idea that we can learn an infinite amount of information by serving as witnesses to people engaged in conversation. Basically, if a person is able to serve as a 'fly on the wall' rather than being in the conversation, there are often a number of things that will be heard that may not have otherwise been attended to. Myself and the other therapists will be the 'flies on the wall' today. We will simply listen intently and reflectively to the Parent Team's conversation so that we can pick out the details more readily.

During your observation, please think about an interaction that strikes you. *It can be any interaction that involves your child. Keep in mind these questions:*

- *What was the interaction?*
- *What struck you about the interaction?*
- *Was it an interaction that reminded you of another time?*
- *Would you have imagined that interaction could have been different?*
- *Did it take you back to a time when things worked better, worse, or just differently?*
- *Were there other interactions that may have been connected to this one? If so, in what ways?*
- *How have you come to know what works best with your child in interactions like that one?*

This Parent Team is designed to be like 'coffee talk'. Discuss the questions as though you and the other parents are simply exchanging information. But, please remember that the 'flies on the wall' are not to be addressed directly and would prefer not to be 'squashed' but rather would like to be as helpful as possible! If the Parent Team wants some feedback to their conversation, we can leave the last five minutes for the therapist team to respond.

If the process proves to be beneficial we can continue these groups in the future.

Regards,

Courtney Olinger

When the parents entered the room after the play group, I reiterated my hopes and intentions and explained the format. The parents of the three boys engaged in a conversation for 20 minutes about what they had observed in the session. The therapist team was also instructed to use the following questions as a guideline for what to listen for while the Parent team spoke. *What struck you about what was said in the Parent conversation? What words, phrases, or images caught your attention? What were those words, phrases, or images?* After the initial 20 minute Parent conversation, the therapist team reflected back by discussing among ourselves while the Parent Team became the audience.

The Parent Team spoke of the skills they had been using at home. One mother talked about the difficulty she had in 'not getting into a power struggle' with her four-year-old son. She explained that her behavioural therapy at home had been challenging in that they learned early on that they had 'to be creative with ways to engage' her son. She had often 'turned teaching moments into games' instead of using typical behavioural techniques that presuppose the adult must have control and the child must comply. This mother had learned early on that the typical methods did not fit for her son. She was clear that such techniques, if continued, only resulted in her son becoming 'overly-frustrated' to the point that the learning opportunity was lost. Games and 'creative methods' on the other hand, engaged her son in a 'mutually enjoyable learning experience'. As this mother spoke about the skill she had developed in utilising creativity for learning, she expressed her concern about each new 'therapy' [behavioural intervention] they entered. 'Watching the power struggle' led her to question if certain services were 'right' for her son and she was unsure whether the therapists would 'be willing to do things differently'. It was evident that this mother had a great deal of knowledge about how to best engage her son in learning and, if overlooked or not considered, the group, the therapists, and her son would miss out on an opportunity to do things differently and engage in learning creatively.

The Therapist Team later acknowledged that they could think of times they engaged in 'power struggles' with a client that, at the time, seemed warranted but most likely were not necessary. It was difficult for therapists to consider that, at times, their methods were less than helpful. Yet, hearing the insider perspective opened the possibility to consider different ways of engaging the children.

During the parent group, the parents also discussed ways that they felt the groups could improve and shared stories of positive things they had experienced at home that they attributed to the group. The Therapist Team, while reflecting, expressed their appreciation for the creativity that the parents had and were eager to incorporate some of the suggestions in later groups. Even more importantly, the therapists were able to express how much they appreciated hearing about ways the group was helping at home and how that was truly valued. This appreciation was validated further when the reflecting turned back to the parents. They articulated that they 'felt good knowing that the therapists actually cared about the outcome in the home and not just in the group'.

Overall, the parents involved in this process felt included in the development of the program and were able to share their ideas for ways to assist their children with play skills. Not only that, but the questions they were asked to consider served as a way to connect what they observed in the play group to real events that occur in their homes and their life. The process served as a way to transport what was happening in the therapy clinic to their lived experience. The play group was no longer an isolated service for these families and was now an extension of their family life because they were able to take a greater role in the service and connect with a sense of agency in determining in what ways this service was incorporated into their life. Additionally, the Therapist Team learned of the many skills and strategies that these parents, children, and their families where already employing. Feedback took on an air of collaboration that allowed for integration of parent/insider-knowledge with the program development.

After this experience, I became more passionate about finding ways to give voice to insider-knowledge. In order to provide a format for the sharing of insider-knowledge, I began thinking of a way to bring parents together. The format that seemed to best suit the purposes of privileging insider-knowledge came from that of outsider-witnessing.

PARENT NIGHT: CIRCULATING INSIDER-KNOWLEDGE

MAY 4, 2008 YOU ARE INVITED

Parent Support Night

• • •

This will be a night to create community and experience new ways of having conversations and listening to the stories of those whose lives have been touched by autism

• • •

I had an extra challenge of situating the group in a way that parents would be open to a different format, as many parent groups pertaining to autism are generally psycho-educational or consist of mainly parent training. In order to address the difference and be transparent about my intentions, I sent the following letter along with the invitations.

*About **TALK to me***

A Parent Support Night

Throughout my time working with children with autism and their families, I have come to know many families that have touched my life in so many ways. My experience of autism has been a pleasant one, as I have learned a lot of ways of connecting with others that I may have never thought of. Autism is something that has in so many *ways enriched my life and my own understandings of the world. I have seen the ways that families put so much energy and time into helping better the lives of their children. I have learned about so many ways that parents embrace their children and hold onto hopes. I have also come to know the great barriers, hurdles, and limitations that can be placed in the way of these hopes. With all of my experiences, my interest in the ways in which families are making sense of life with autism has grown. I have had the opportunity to hear many stories that speak to me. They are stories of compassion, determination, acceptance, caring, and love.*

It is my hope that there will be an audience for these stories that extends beyond myself. My intention is to co-develop a community of parents that would be able to transcend the ideas of media, clinicians, and service providers by creating a platform in which families can speak about **their** *experience and how* **they** *think about autism. As part of this platform, I imagine creating an audience that can listen and attend to the multiplicity of experiences and be able to connect with other families in a way that encompasses accountability, respect, and support.*

I hope to have the opportunity to engage in conversations with parents that will be helpful in navigating a life with autism. I have thought of you and your spouse for the trial meeting because of my previous experiences of openness and collaboration with you.

With Hopes,

Courtney Olinger

Parent Night consisted of three therapists (two familiar with narrative practices), one couple (mother and father), and two mothers. As a way to bridge the gap that may exist between myself and my clients because I am not an insider (I do not have a child diagnosed with autism), I invited a narrative colleague of mine, Anne Arnold, who is also a parent of a son (age 22) who has wrestled with autism.[1]

Additionally, in an attempt to build in a way that the professional world be audience to the knowledges of insiders, I invited another colleague who is a behavioural therapist and is not familiar with narrative ideas. All other parents who participated had one child with autism, between the ages of four and seven.

Once the parents arrived, I reiterated my intentions and hopes for the group and explained the format and provided them with a list of questions to consider when speaking and listening.

- How have you come to know what works best with your child and for your family?
- What have you come to know about ASD? What knowledges and skills have you acquired over your journey regarding ASD, your child, and your family?
- As you listened, was there anything that struck you as important or connected you to your own experience? What caught your attention about what was said?
- What thoughts or images came to mind as you listened?
- Did what you heard bring you back to any experiences you have had with your own journey with ASD? What was that thought, image, experience?
- Were you able to connect what was being said to your own experience or was it different? What was it that was being said that struck you as different or similar?
- Does this lead you to any questions that you have already been considering or find new to consider? What are these questions?

We began the group with introductions. I took special care in introducing Anne, the other narrative therapist, and made efforts to be transparent that she would help me run the group so that we could stick to the format of outsider-witnessing (White, 2007). I wanted to take special note of her role as an insider but do so in a way that would not create a hierarchy or set up a power differential. The following are some excerpts from Parent Night.

THE INITIAL CONVERSATION

The initial conversation took place between Anne, who is also the mother of a son (age 22) who has wrestled with autism and a mother ('Mom 1') of a boy with autism (age four). The outsider witnesses consisted of two therapists of children with autism (myself and a behavioural therapist), a mother and father of a boy (age seven) with autism, and one mother of a boy (age five) with autism.

Anne: What were your hopes in coming here today after you received the letter?

Mom 1: Trying to think of, in what ways are we bridging the parent-therapist gap? When I was getting ready I was thinking, 'I wonder what it is that therapists think about things'. I think that would be interesting for us to know.

Anne: Do you find that the therapists, or other people involved in your child's life, listen to you?

Mom 1: Yes, much more than I had anticipated. We had very good luck with that. My experience has been that in talking with other parents, people don't always find that to be true. Or perhaps they are a little bit more timid about bringing up topics with the therapists. I have always had good experiences actually in a bunch of different settings in terms of them wanting to work with us and not wanting the worlds sort of separate.

Anne: Do they (therapists) listen to your ideas?

Mom 1: They at least pretend to. [laughter] I think they have. We have changed his programs around based on things that we said, you know this is sort of the 'static point' and we have to change it up for him to be successful. My son is especially prone to getting bored or distractible when he feels that things are at the same level. So he does really well with change – changing emphasis, changing enthusiasm, changing the environment. He likes that. Which is wonderful but it can also be a challenge. We have to figure out why he is getting distracted and how to deal with that successfully. So we were really lucky to have people to work with us on those things along the way.

'Mom 1' then asked Anne about her experiences. As Anne spoke, she was diligent in positioning herself as someone that had very different experiences, mainly based on some changes over time. Here are some excerpts from that conversation:

Anne: I don't think I trusted that people were interested in my ideas as a parent. You have to remember that was a very different time, but the word 'autism' conjures up a predicted outcome. You hear that diagnosis and that's it. You see that one thing in your mind. Everybody else sees that, family sees that, friends see that. I did not want that …

I had to be really creative but I did not feel like other people supported the creativity …

I talk with a lot of parents about autism now. There are a lot of ideas, but a lot are still based on, 'This is the only way you should do it'. There are just so many ideas about how to do it but they all think it's the right way. It is really hard to negotiate it. You know, 'Should I go this way? Should I go that way?' I just think, 'How do we get through the next day?' …

People [parents] may share stories about treatment and where they are getting services but I do not really hear parents sharing their ideas about *how* to do this.

As the conversation progressed, some of both mothers' knowledges were further developed and explored:

Mom 1: We talk about how some of these tests are sort of superficial in terms of standards and such. But everything is pretty uncertain in terms of research. Finding that right path is tough but still there are always more options. I don't like statistics [regarding long-term 'functional outcomes', such as those regarding marriage, college graduates, etc.] and I try to turn them off and it's not easy. Numbers scare me … they irritate me more. [This mother wanted me to clarify what statistics she does not like. The portion in brackets was her addition to clarify what statistics she tries to turn off.]

Both mothers clearly had different experiences but were able to connect around a common theme of wanting to do best for their child, even in the face of modern dominant ideas and powerful discourses around science and research. Anne also addressed how such dominant ideas led her to seek isolation to protect her son. Even though her experience was located in a different temporal realm, she was able to connect with some of the ways in which dominant discourse and expert notions can silence parents:

Anne: I don't want to carry around a predictor that it will turn out bad. And I have kept quiet because I know we all have different experiences and I do not want others to think I know what their experiences is or that I think it is the same.

When asked about ways that parents deal with disparaging effects of dominant ideas (such as outcomes and statistics), 'Mom 1' shared some of her knowledges around ways to hold onto hope.

Mom 1: Parents seem to seek me out. They call me if they are having trouble with services. That is what I did at first. I would talk to other parents that went through it and get a sort of road map from them …

Holding onto the little steps as he has progressed helps. You see more hope.

After about 40 minutes, the initial conversation ended and the outsider witnesses engaged in a conversation about what they had heard. 'Mom 1' and Anne now became witness or audience to the conversation. The outsider witness group spoke of the parts of the initial conversation that connected in some way to their experience, in terms of similar situations, thoughts, feelings, hopes, and questions, as well as what was said that may have been different or sparked their curiosity in a different way. As part of the witness team, I was able to guide the conversation by asking questions. In this way, I attempted to stay away from advice-giving or burden-sharing and directed the conversations toward further articulating some of the knowledges and skills that the parents in the group had developed.

Mom 2: (son, age five) We look at our son under a microscope. We analyse every little thing that he does and then when we ask others they say he is fine. And with the typical preschool and a great teacher's aide, the [regular education] teachers tell us that if they had to pick the kid in the class who has autism it would not be him. It sounds good but still we have our doubts.

Courtney: Are there other messages that you get from that? In what ways does that doubt work on you?

Mom 2: Well, people tell me he is doing fine. But I clearly know he still has autism. It is very obvious to me and so it makes me not doubt the teachers, because they are incredible teachers, but they just don't know autism. They don't know how to pick up the nuances. And thankfully we have a wonderful aide who is incredible at picking up the nuances. If she didn't then there'd be a problem. Maybe he is typical-ish now, but in a year's time if they are not dealt with he is worse off and it's a problem.

Courtney: Do you find the nuances mostly have to do with social things?

Mom 2: Sometimes, like if a kid tries to take his hat he is just lost. And the aide only has to step in to give him a trigger, and he knows, 'Okay, I know what to do now'.

Courtney: Does this help you hold onto hope?

Mom 2: It does. I think he will be fine. I think we just will always have to work.

Courtney: What's it like to have to juggle all the different services and all the different advice? What sort of things have you done to juggle this?

Mom 2: The best advice I got from a mentor is 'go with your gut'. If you make a mistake you can quickly change it.

Courtney: It seems like 'to go with your gut' would be very challenging. Is it?

Mom 2: It was. My husband initially put a lot of emphasis on what the professionals said, but then compared it to what he really felt and we finally figured out that we had to go with our gut.

Another mother ('Mom 3', son age seven) in the outsider-witness group asked some of the questions she had been considering as she listened to the initial conversation. At first, she was filled with sadness but after some questioning she and her husband ('Dad') were able to express the ways they had found comfort together.

Mom 3: Does it ever scare you that we always kinda feel that we have to be there to kinda prevent and help … sometimes I think, 'Okay, someday he will grow up and be able'. That is when I feel relaxed and, 'Okay I do not have to be alive for the rest of their life and that they will always need someone to protect them'. You know, eventually when they grow up, will they be able to take care of themselves? I am not so sure … I love to make friendships with women that have autistic children that are older because I hear their stories and it gives me hope that eventually I won't.

Courtney: Is there something about what you heard, having heard a mother with an older son, that calms some of your worry that you will always have to be there with a helping hand?

Mom 3: It's a double-sided blade, sometimes it relaxes me and gives me hope and sometimes it's very unsettled because I am always thinking, all the children are different. I know of some that cannot be without their mom and some I hear are fabulous and live by themselves. I just hear so much … I guess sometimes isolation sounds kinda nice. But it is very scary and frustrating to talk about the future. I feel I am never prepared enough. How could I be? [pause] I want so much for them to not be alone … The friendship that we talk about for the kids. It's just so important … [silence]. There are days I think he will do very well. He is very social but now he is going back to kindergarten for a year and I am frustrated but I think, 'Don't be'. You know, he has the social piece and eventually the school, the math, and the reading is not going to be that important. He gets frustrated. I want him to be in an environment that he feels safe and comfortable.

Dad: Why should we put him in a situation where he will just fall apart? He just does not get things. He will try something over and over again and not get it. And as soon as someone shows him how to do it he can but he never figures out to try something new. It's okay if he needs a little extra help.

Mom 3: If we wait for him to feel comfortable he will learn better. We have to be patient. He's not brilliant. Of course it bothers me that he is not moving forward in school. I just try not to let it. He is just lovable and happy and every day he wakes up and it's a beautiful day, so I tell myself that it's okay he's not going onto first grade.

Courtney: You've mentioned frustration and worry for your family and yet it seems you are finding ways to counteract those. What are some of the ways you are doing this?

Dad: Normalcy. Going to work. When [Mom 3] has been really upset, keeping a level personality helped to stabilise the family?

Mom 3: We keep trying everything we can. I just feel like there is never enough therapy and we will keep trying everything.

To complete the outsider-witnessing experience and Parent Night, the outsider-witness group came to an end and 'Mom 1' and Anne had the opportunity to respond with any reflections or clarifications.

MY REFLECTIONS

The biggest challenges of Parent Night were ways to keep the format from becoming advice-giving or further emphasising any one knowledge over another. I found the parents were eager to advise and cheer each other on; which was pleasant, but had the danger of placing the parent being cheered or advised in a lesser position. At these times, I attempted to redirect the conversation with questioning each parent about their own experience and what they were already doing. I was pleased that all the participants had the opportunity to engage in a different conversation about the experiences of autism. Bridging my passion for making insider-knowledge forefront to the work in a context that is generally informed by western ideas of expertise, is a huge challenge. I have to constantly consider how my questions and the format influence the clients. I hold fast to the notion that my role is to assist families (all members involved) to re-connect with agency in their lives. This means I need to diligently and intentionally find ways to privilege their voice.

The aforementioned strategies are my creative attempts to do so in a context and society that has not often challenged the practices of professionals or expert knowledges when addressing work with those connected to autism. Narrative practices have provided me with a basis for such creativity and a collaborative stance to develop ways of working that are intentional and insider-informed.

I will now include a collective document of the insider-knowledges articulated by parents during these groups.

PARENT KNOWLEDGES: A COLLECTIVE DOCUMENT OF INSIDER-KNOWLEDGES OF PARENTING A CHILD WITH AUTISM

As a narrative therapist, it is important to me that I find ways to continually reduce the influence of dominant discourse that elevates the status of a professional and diminishes the status on the client(s) (White, 2007). I take several steps to remain de-centred and influential so as to bring forth insider-knowledges. This means I am mindful not to take on a role of the 'all-knowing expert' while being aware and openly acknowledging that I do have knowledge and skills that I can utilise to be helpful to others who seek my services (White, 2007). The following are just some of the insider- (specifically parent-) knowledges that I have come to learn about when working with children with autism and their families.

I have compiled them by looking back through transcripts and notes taken during various therapeutic sessions with families of children with autism (including play groups, parent night, behavioural consultations, and family therapy). Whatever the context of my services, my questions are guided by my narrative theoretical stance and geared toward the deconstruction of dominant discourse in hopes to uncover and cultivate insider-knowledges. In reviewing these transcripts and notes, common themes were discovered. I have attempted to represent these themes according to key words that I heard expressed by clients. I have further sought to bring life to these key areas by supporting them with stories that were shared by clients.

It is my hope that a collective document (see Denborough, 2008) can serve as a way to circulate insider-knowledges and hence elevate the status of the parent to that of 'expert'. Perhaps other parents will find these 'expert parent knowledges' helpful and be able to add some of their own expertise along the way.

Be creative. Find people who will support creativity in helping our children: Some of us have found ways to be creative with our children. We have found comfort and collaboration with others who have supported such creativity. Our children are constantly changing. They need to be motivated and challenged. This often requires a great deal of creativity on the part of those who work with our children. This fosters enjoyment and engagement.

One mother told me her son had 'burned out' on the typical methods of working with him. Things that worked before were suddenly not working and things he had liked were now bringing struggles into their lives. He was upset a lot and it was concerning the mother. She spoke of how she found that constantly changing the environment really helped. She learned to use her creativity to engage him in new ways. The struggles stopped and she found that there seemed to be more enjoyment in the things her son was now doing.

Talk with a lot of parents about autism. Seek other parents out: Talking with other parents of children with autism helps many to feel less alone. Other parents can provide information, resources and insight as a guide, especially when a new diagnosis is received. Often parents tell me that one of the things that helped them get through hard times was seeking other parents out.

One mother told me that after speaking with many doctors and nurses for years and finally receiving a diagnosis, she felt confused and unsure of the medical profession. She searched for other parents to help her hold onto hope. She still remembers one mother's supportive words of encouragement. She says that was a turning point for her and she will never forget this mother.

Make friendships with women who have autistic children that are older. Their stories are an avenue to hope: Many mothers have found enduring friendships with other mothers who are experiencing raising a child with autism. These friendships are more than just guidance or advice. Many mothers speak of the comfort and a sense of hope in sharing experience with other mothers. Sometimes, building friendships with mothers whose children are older provides insight into experience over years. This often lends to the sense that they will get through the tough times, that 'their children grew and overcame challenges and so will my child', and that 'others have done it before so I can do it too!'

One mother specifically spoke of friendships she valued that were with mothers of children, also diganosed with autism, who were older than her own children. She told me she found this hope in the least likely place – waiting for her son in the waiting room. At first she felt like she would be better off if she left to run errands during the hour-and-a-half but one day she saw an older boy come in with his mother. The boy went with his therapist and the mother sat down beside her. The two of them spoke for the rest of the time. She said she learned more from that mother than she had from several doctors. She listened to the mother's stories about her now-grown son and began to see glimmers of hope she had not seen before. She treasured that hour and now never left while waiting for her son because she did not want to miss the opportunity to meet other parents. She was able to spend more time with the first mother when she was also in the waiting room as well. Their friendship grew and she held onto the hope she gained through their conversations.

Give anything a shot. Try anything that is benign/not going to hurt your child. If you see progress, keep going: There are numerous forms of treatment and intervention for children with autism. Parents are often committed to trying anything and everything they can. Many parents spoke of constantly searching for benign treatments, getting advice from other parents and researching what is out there. The commitment to continue is helpful for many parents and several parents said, 'If it works, keep going. If not, find something else.'

'Go with your gut': *One mother told me that this statement 'go with your gut' was the most valuable piece of advice she had gotten over the years. She and her husband had often received conflicting messages from professionals or had been faced with multiple options. They had relied on their gut for several years, greatly reducing the influence of confusion, fear, and judgement.*

Questioning who says what our child is supposed to be accomplishing: Differing ideas about what a child should be doing are often overwhelming and sometimes conflicting. Questioning what others say is helpful for some parents. It helps for some parents to stay focused on what they think is important, to recognise and revel in the little progress and accomplishments made, and to resist feelings of confusion, frustration, or disappointment.

A mother and father were telling me of the difficulty they were having with the school and the Individualised Education Plan process that was supposed to be determining what supports their son would receive at school. They were confused by what their son should be doing at his age and feeling disappointed and frustrated that they were hearing he was not doing several things. On top of that, the speech therapist and the teacher did not seem to be in agreement about what their son was capable of and what he should be doing. They grappled with the information they received and felt torn about what to do. They were hearing many messages from the school about what he should be doing that invited Disappointment but they were experiencing Hope and Pride from the *accomplishments they were seeing with their son at home and with the therapies he was getting outside of school. Questioning who had the power to say what their son should be doing helped them to refocus on Hope and Pride. They relayed to the school the accomplishments they were seeing at home and told the school they wanted to focus on continuing those.*

Focus on the functional outcome not what someone decides is typical: Functional outcomes are the things that will help a person have as fulfilling a life as possible. This may be different for every person and is often different from the many ideas about what is 'typical'. Some parents have seen more hope when they focus on functional outcomes and are not bound by dominant ideas about 'typical' or 'normal'.

A mother expressed her concern about what professionals say is 'typical'. She said that she often wonders if they really know what 'typical' children are doing and who has the authority to decide what is 'typical'. Such questions have led her to re-evaluate the focus on helping their son 'be typical' and instead 'focusing more on developing the skills that will help him to manage everyday life'.

The academics are not the most important thing: *A mother told me that her son was being 'held back' in school for another year of kindergarten. She was originally distraught with the news because this was not the typical course of action. Then she rethought and decided, 'The academics are not what's important; what's important is that he can experience success with what he enjoys, what makes him happy'.*

It's okay if he/she needs a little extra help. It's okay if it takes him/her a little longer to get it: Some parents have expressed some frustration in witnessing their children struggle to learn or master a new skill. It is common for teachers, parents, and other service providers to use 'supports' for the children to learn, such as picture icons, breaking down tasks step by step, or other modified curricula. Many children with autism learn best this way. Sometimes, progress may take longer than with other teaching modalities; yet, the children are still learning.

One father told me that he was originally very confused by the modified curriculum. All the pictures and supports were so different from what he had known that he was a little frustrated with his son's 'reliance' on them. When he started to see his son really grasping new concepts, however, he was really excited and proud. Having that experience changed his view.

Focus on the positive things. Don't let the focus be on the idea of detrimental outcomes. Hold onto the little steps as they progress – you see more hope: Parents have spoken about the power that 'negative' ideas or focus on difficulties can have in their lives. Many have noted that focusing on positives, no matter how small they may seem, can help them to hold onto hope. Additionally, many parents have found that focusing on the positive things have changed their general outlook on life by adding an extra appreciation of the small things in life.

Do not be bound to testing standards or research. 'Turn off' statistics. Don't carry around a predictor. Know there are always more options: There is a great deal of research, statistics, and standards regarding autism that are circulated throughout society. Often these present a gloomy outlook or paint a less-than-favourable picture. 'Turning them off' can be helpful to parents to not fall prey to dominant stories of hardship and struggle. Similarly, research, norms, statistics, and prognoses are dominant ideas that suggest that there is a true and ultimate outcome. Parents often warn against adopting these as a 'predictor' of what will be for their families. There is always another story and every parent has the ability to develop what that story will be for their child and their family.

Keep 'imperfections' of all children, even 'neuro-typical' children, in mind: Keeping in mind that all children have struggles can be helpful for many parents. One mother told me, 'Every child has a time when they become upset. They may tantrum, they may have some sort of behaviour. All kids do that.'

Pick up the nuances/signals that something might be difficult for them and know what small cues you can give them to be successful: Getting to know each child is important. There will be certain things that work for one child and may not be as helpful for another. Parents are often experts of picking up the small nuances that suggest their child may be struggling. Equally, they develop expertise in knowing what strategies can be helpful for them to succeed. This is so important for professionals to consider as parents often have small clues that professionals might otherwise be unaware of.

A mother contacted me to let me know that her son was coming home from our play group and 'falling apart'. She said she knew that he probably held it together well throughout the group but that the difficulty of the demands placed on him were most likely setting him off once he got home. She suggested that she observe the group so that she may be able to pick up what it was that was difficult for him. After her observation she was able to relay to myself and the team what signs would show us that he was really overwhelmed and simple phrases that would help him. Without her assistance and expertise, we would never have picked up on the subtle cues that he was struggling and would not have been able to help him.

Sometimes 'isolation' is okay: Isolation has developed a negative connotation, especially when it comes to families of children with autism. It can be an unwanted effect or result that comes about based on fear or overwhelm. But sometimes 'isolation' can be chosen and helpful. Some parents have suggested that isolation can help them to sort out their thoughts, reduce the confusion of so many voices and opinions, and simply bring in some quiet. Sometimes isolation is individual; sometimes it is of the family from the outside world. Parents have also recognised the value in individual isolation from time to time in their own lives and this has led them to consider that isolation for their children may be necessary and beneficial. To what extent isolation is carried out in a helpful manner will depend on each individual and each individual family.

Develop an environment that he/she feels safe in and is comfortable: Safety and comfort are very important for several families. Sometimes this means using not-so-conventional settings.

One family struggled for years to get their son to fall asleep or sleep through the night in his bedroom. However, they noted that he would often sleep in his stroller or in a car seat. They decided the feeling of being contained must be relaxing and comforting to him so they set up a tent in his bedroom with a mattress in it. Their son now sleeps peacefully and does not resist going to bed.

Give other parents a road map: Many parents of children with autism find that offering help to other parents can be a therapeutic and empowering experience. They see the importance in helping other parents so that struggles can be minimised and they report feeling as though they have 'given back' by setting other parents up with resources and support. A road map can be a great starting point and guide.

Be patient: Patience is often cited as a valuable tool that can be utilised in dealing with struggles. Patience can help parents to manage the multiple stressors of raising a child with autism, raising other children, and managing multiple relationships. Couples often suggest they develop greater patience as a result of the experiences they have raising a child with autism.

Parents as a team: Parents of children with autism have added struggles because of the financial demands, the multiple services, and the tough schedules. Working as a team is important in managing struggles. *The following are just a few suggestions from parents: listening and mirroring, discussing bills and making decisions, understanding each other's point of view, and holding each other.*

It is important to build in other forms of support: Parents talk about other people in their lives who are great contributions to knowledge and support. *They suggest: 'Have people in life that are respectful'; 'It is important to have family around and people that are supportive'; and 'Read a lot of books'.*

'Let yourself off' a little bit/not have to hold to such high standards: Parents can find some solace in reducing the expectations they have for themselves and their partners. Sometimes it is important to 'let yourself off the hook'.

One mother told me that she had been striving to 'be perfect' in her management of the different *medical appointments, therapies, educational services and the suggestions that each gave her in dealing with her two children with autism. This drive for perfection was weighing heavily on her and inviting a great deal of judgement and distress about her own abilities. When she decided to 'let herself off a little bit' she immediately felt some relief and recognised the value in 'lowering her standards' for herself.*

Hold onto hope: Parents often reference Hope as a major factor in helping them get through difficult times. Sometimes this Hope is found in learning about stories of other families' successes. Sometimes it comes by way of support from other parents of children with autism or outside supports. Sometimes it is found in the small gains that the children make. Whatever the source of Hope is, it is often talked about as an integral part of living in the world of autism.

Parents have had several suggestions over the years about ways to hold onto hope. When one mother was faced with a difficult situation that threatened to rob her of her sense of pride in her daughter's achievements, she decided to 'refocus her attention' by decorating a bucket with pictures and words that reminded her of all the amazing qualities and achievements she had come to know in her daughter. She could then continue to fill the bucket with other things that represented such achievements. The bucket would serve as an ongoing way to refuel Hope. Another mother found that a journal of 'the small steps' was helpful in renewing Hope. She could not only visually see the plethora of gains that were adding up but also go back and review them whenever she wanted to remember how far they had come and that progress was possible. Yet another mother held onto Hope by seeking out stories of other families' successes.

NOTE

1. I feel it is important that I mention Anne's desire to be identified in this paper. In my interest of collaboration and continued commitment to respect and honouring of all voices (parent and professional), I sent out several copies of this paper throughout the writing process to inform the parents and professionals involved. It was also my intention to stay as close to the experience of those who I am referring to. Anne requested that I identify her, stating 'I spent so many years in invisibility around [my son] and autism because there was no other way that I knew to protect us from the more powerful ideas of what I should be doing to him that to remain invisible seems like more of the same'. Anne's request spoke to me, not only because of my desire to include those I consult with in my writing but also because she was taking steps to break the invisibility which no longer fit for her. She also consulted with her son who requested that I speak of him as 'having wrestled with autism'. Again, I want to honour the representation that fits his experience.

REFERENCES

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Avdi, E. (2005). Negotiating a pathological identity in the clinical dialogue: Discourse analysis of a family therapy. *Psychology and Psychotherapy: Theory, Research and Practice,* 78, 493–511.

Centers for Disease Control and Prevention (CDC)(2007). Autism Spectrum Disorders (ASDs). Retrieved from http://www.cdc.gov/ncbddd/autism/

Denborough, D. (2008). *Collective narrative practice: Responding to individuals, groups, and communities who have experienced trauma.* Adelaide, Australia: Dulwich Centre Publications.

Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings 1972–1977.* (C. Gordon, Ed.; C. Gordon, L. Marshall, J. Mepham, K. Soper, Trans.). Harlow, England: Pearson Education.

Kemmis, S., & McTaggart, R. (2008). Participatory action research: Communicative action and the public sphere. In K. Denzin & Y. Lincoln (Eds.), *Strategies of qualitative inquiry* (3rd ed.) (pp. 336–395). Thousand Oaks, CA: Sage Publications.

Law, I., & Madigan, S. (1998). *Discourse not language: The shift from a modernist view of language to a post-structural analysis of discourse in family therapy.* In S. Madigan & I. Law (Eds.), (1998). *Praxis: Situating discourse, feminism and politics in narrative therapies* (pp. 1–12). Vancouver, Canada: Yaletown Family Therapy.

Sween, E. (1998). The one-minute question: What is narrative therapy?: Some working answers. *Gecko: A Journal of Deconstruction and Narrative Ideas in Therapeutic Practice,* (2), 3–6.

White, M. (2007). *Maps of narrative practice.* New York, NY: W. W. Norton.

World Health Organization. (2009). *International statistical classification of diseases and relational health problems* (10th revision). Retrieved from http://apps.who.int/classifications/apps/icd/icd10online/