Family Engagement

A View From the Front Line and in the Trenches

by Tina Szymczak
About Me ..
What About You?
In the Beginning . . .

- Married June 1995. Struggled with infertility
- Turned to Adoption
- Completed Adoption Training in Dec 2001
- Matched with a little boy in April 2002
- Adopted again in 2005 an 18 month old boy
What We Knew

- Sporadic care
- Mother deemed unfit
- Ways of coping
- Anxiety
- Response to discipline
- Developmental level
- Self-Regulation concerns
What I Thought I knew

- I had work experience
- I thought I understood about attachment
- I thought I knew how to access any services we might need
- I knew that “love” was not enough
What I Didn’t Know

- Effects of toxic stress
- Stress shown by behaviour
- Longer term challenges
- Chronic anxiety & Aggression can predict later mental health

Ontario Centre of Excellence for Child and Youth Mental Health
A Few of the Services We Accessed

Speech Therapy  Occupational Therapy  Resource Consultant  Behavioural Services

Social Worker  Childcare  Psychologist  Pediatrician

Psychiatrist
Multiple Diagnosis vs Labels

- ADHD
- OCD
- BiPolar
- Attachment
- SID
- TS
- Dysfluency
- ASD
- Intellectual Disability
What Did I Really Need as a Parent at First?

A Magic Wand  Someone to Listen

KEEP CALM AND Listen Carefully
What does a week in the life of a family with mental health challenges look like?
VIDEOS

Mental Health Struggles

►https://youtu.be/pHa6cEKu_oQ

►https://youtu.be/rOA48DT7vTY

►https://youtu.be/UCwGzcd-Ef0

►https://youtu.be/FifauOHce-k

►https://youtu.be/v3HpvjZS4kQ
“... common sense and ordinary human decency are at the heart of positive partnerships between families and professionals serving children with disabilities”

Myths

“It is not my job to remind caregivers of appointments”

“Proper communication with a family should occur over the phone or in person only”

“A family that doesn’t follow through with service are in denial and/or not invested in service”

“Frequent cancellations indicate the family does not want service”

“A family mandated to participate in treatment are never really engaged”

A family that attends sessions regularly is engaged in services
What Can We Do - Individually

- Move beyond our labels into friendly interactions
- Find common ground
- Listen!
- Let me talk about the future - it weighs heavily on my mind
- Share - knowledge, resources, strategies
- Relationships need time to develop
- Consider family as a whole, not just the needs of the 1 child
- Don’t judge us (we can tell if you are)
The Way To Help Someone Feel Better

https://youtu.be/l2zLC
CRT-nE
Frantic Mother

https://youtu.be/A1AIroyiLEM
What More Can We Do For Families?

- Find out what we prefer to be called, do not refer to us as “mom” or “dad”
- Do not take anger personally, often it is an indicator that more patience and conversation are needed
- Remain calm
- Encourage parents to be actively involved and even in control of services they receive
- Admit when you don’t know something and then find out!
- Be reliable and build trust
- Stop being dismissive by claiming we are in denial
Harry (1997) has suggested that when professionals use the term “in denial” what they are really saying is that the parents and professionals are “in disagreement” over the diagnosis, prognosis, or intervention plan.
Early Treatment Strategies to Improve Engagement

- Appointment reminders - if your dentist and chiropractor can do it why can’t mental health services?
- Saturday and evening appointments
- Assist with obstacles - child minding, transportation,
- Reach families in the ways they want: online (e.g. Skype), email, phone, podcasts
- Group seminars where they can take one, many or all in a series in person or online
- Meet in the community closer to a family's home or even in their home (Early On, library, park etc)
- Learn about the cultures of the families you serve - it is important to know their mindsets toward mental health challenges and other factors that might impact treatment
- Offer services in the languages of your clients whenever possible (e.g. partner with multicultural services) to not only have 1:1 interpreter but also to offer seminars and groups
We Need to Learn and Provide Culturally Informed Practices
What Do Families Want You to Know

“Believe me when I tell you something is not right with my child, don’t make it take 2 years before we have a diagnosis.”

“Accept and respect when I feel the need to advocate for him/her”

“I understand there are waitlists, help us to fill the wait with meaningful steps forward for our child and family”

“Don’t dismiss us with the idea that we are “in denial””
“Many of us with children who have diagnoses of mental health disorders or mental illnesses noticed concerns before the age of 6 years, but were unable to get the supports and services needed to effectively intervene and minimize the impact of these diagnoses for our children, our families and our communities”

-Supporting Ontario’s Youngest Minds, Ontario Centre of Excellence for child and Youth mental Health, 2014
What Does Research on Early Years Tell Us?

- The prevalence of any mental health disorder for children 4-17 years of age is 14% (Waddell, 2007)

- The existence of chronic anxiety and aggression in childhood, even when not formally diagnosed, can predict the presence of a diagnosed mental disorder later in life (Fryers and Brugha, 2013)

- Some research suggests that later mental health problems can be predicted as early as five months of age if infants are exposed to multiple risk factors (Tremblay et al., 2004)

- 21-50% of children with special needs present with mental health challenges (Supporting Ontario’s Youngest Minds: Investing in the mental health of children under 6, Clinton et al. 2014)
Low Family Engagement

Low family engagement and retention are significant problems for mental health prevention and intervention programs. Anywhere from 20 to 80% of families drop out prematurely.

- (Ingoldsby, 2010)
Reasons Why Families Don’t Engage in Treatment

Let’s list some of the reasons families give for not engaging

Let’s discuss some other reasons that we believe, as clinicians, are further reasons for not engaging

What could we be doing differently to engage more families and for longer?

Let’s discuss in our groups
5 Components of Family Engagement

- Treatment Relevance and Accessibility
- Cognitions and Beliefs About Treatment
- Daily Stresses
- External Barriers to Treatments
- Therapeutic Alliance

Staudt, 2007
Predictors of Lower Rates of Engagement

- Single parent status
- Ethnicity
- Low income/resource neighbourhood
- Parent mental illness/disorder
- Practical obstacles (e.g. location, lack of transportation)
When I Was Young
A Lifetime of Anxiety and Depression
Through Parenting two Very Spirited Boys I became . . .

Isolated
I Stopped Taking Care of Myself

- I gained 40 lbs in a short time
- Stopped going to Doctor and Dentist appointments
- I did very little physical activity as my boys were exhausting
- I began to “shut down” my emotions in order to deal with what was going on.
I Developed Diabetes & Sleep Apnea
I Fell Into a Deep Depression
Daily Medication
Regular Therapy
Making Sure To Do Things I Enjoy
What Kind of Parents Were We While We Dealt With My Mental Illness?
Mental Health for the Whole Family

WHAT IS AVAILABLE FOR THE PARENTS

RECHARGING BATTERIES

SIBLING SUPPORTS AND SERVICES
Therapeutic Alliance

- Communication
- Commitment
- Equality
- Skills
- Trust
- Respect
Reference List


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