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Submission by Youth Affairs Network of Queensland Inc
to the
National Health and Medical Research Council
on the
Draft "ADHD" Clinical Practice Points

This submission is written out a desire to protect children. It is written to advocate for the right of children to grow up with healthy bodies and clear minds. It is written as a plea to celebrate the diversity of children and to view their unique expressions as precious gifts, rather than describing them as "sick" when they don't conform, obey or please adults.

History has taught us the lesson of "The Big Lie". Whole societies have bought into ideas and concepts that have later proven to range from baseless to maniacal. Reading with any sort of an open mind through the voluminous literature on the topic of "ADHD" in the early 21st century, one cannot help but be reminded of reading through treatises on slavery in the 18th century. How could something so horrible and so egregious be happening in a "civilized" society? Why didn't those people take a hard look at what they were doing?

We have no doubt that someday people will look back on the massive drugging of children in Australia in the same way. "ADHD" is a catchall description of childhood behaviour invented by people sitting around a table who stood to benefit by the diagnosis both professionally and financially. Virtually any child who has ever been a problem for any adult, could qualify for this "diagnosis", and be declared "sick" in the absence of any medical, scientific or organic findings whatsoever. Yet despite the indisputable fact that no one has been able to tell us what "ADHD" actually is, millions of parents, teachers and doctors are accepting it without question and supporting the use of powerful cocaine-like drugs in children. Meanwhile, pharmaceutical companies are reaping hundreds of millions of dollars in profits. When dissidents try to speak out they are either ignored, discouraged or attacked with the viciousness historically characteristic of those profiting from a "Big Lie". When the information does get out to the public, we are told to discredit it as "fanaticism" or "extremism". Ultimately truth is the greatest enemy of the "Big Lie".

A MORATORIUM ON "ADHD" DRUGS

The Youth Affairs Network of Queensland Inc (YANQ) is one of many groups, practitioners, politicians parents and individuals concerned about the alleged increase in cases of 'attention deficit hyperactivity disorder' ('ADHD') amongst young people in Australia. A wealth of medical and psycho-social evidence points to the deficits of the 'diagnostic criteria' presently used to diagnose "ADHD" and the damaging side-effects of the stimulants prescribed to manage the 'disorder'.

YANQ is concerned that the development of the Clinical Practice Points serves to endorse a "medical model" that tells us that children with challenging behaviours have a mysterious "mental illness" and should be restrained with powerful and dangerous drugs. Thousands of medical professionals around the world have rejected the "ADHD" diagnosis and believe it is harmful to label children in this way.

The pharmaceutical companies make billions of dollars annually selling drugs for this phantom "disorder" all over the world. Australian children are learning that they are not responsible for their own behaviour, and that drugs are the answer when they have a problem. They are suffering serious short and long

term side effects, including the “zombie” effect that can compromise the joy and spontaneity of childhood. The Draft Clinical Practice Points serves to legitimise diagnostic criteria for the so-called disorder that includes such vague statements as “is often "on the go".

Drug companies profit if we believe in “ADHD”, and children with challenging behaviours are stifled by these powerful and dangerous drugs. But common sense tells us that we must protect our children from the physical and psychological dangers of this highly questionable diagnosis and the drugs used to “treat” it. In light of the lack of solid scientific evidence about this “disorder” and the disagreement among professionals about its validity, YANQ renews its call for a moratorium on the use of “ADHD” drugs on our children.

When a child is misbehaving, and they can be identified as “sick” and drugged into compliance, the parents no longer have to feel guilty or inadequate, the teachers no longer have to struggle with constant problems in the classroom, the physician has an ongoing customer and the drug company has branded another cash cow. Everyone is happy, except for the child. The child is blamed within the family as the source of the problems, stigmatised and disempowered by the diagnosis, and has to suffer the powerful short-term side effects and possibly the scary long-term side effects of the medication.

No one knows the aetiology of “ADHD”. That is a fact, and any honest professional, regardless of how strongly they support the biomedical model, will concede as much. For well over two decades, drug companies have poured millions of dollars into research seeking the “smoking gun” that will “prove” the existence of “ADHD”. Periodically, we hear about some “exciting” research, only to find out later it did not hold up under further scrutiny. In fact, the flimsiness of some of this research, and the ease with which it falls apart when others attempt to replicate it, raises concerns about the motives of the original researchers, given their funding sources. Yet even today you will find some proponents who, while admitting we don’t know the causes of “ADHD”, will tell you how confident they are that some new theory will eventually prove valid.

SPECIFIC CONCERNS WITH THE DRAFT CLINICAL PRACTICE POINTS

There are a few areas that deserve special focus. Firstly, the behaviours described in the diagnostic criteria are normal childhood behaviours, or at worst, the normal behaviours of children being difficult. How many of us have not had difficulty sustaining attention, especially to tasks we found boring? How many of us haven’t been forgetful, disorganized, easily distracted or had difficulty waiting our turn? How many of us have fidgeted? A “disease” has actually been constructed around such things as avoiding or even just being reluctant to do homework, losing things and not finishing chores! Virtually ANY child, other than the most compliant, passive and inactive, could qualify for this diagnosis, and that is the way it was designed. That explains why more and more children are able to meet these absurd “criteria” every year.

Secondly, since when is it a “disease” to not obey and comply? Several “symptoms” (e.g., 1d, 2b, 2c) specify behaviours where a child isn’t doing what they are told. When did disobedience become an illness? Similarly, how can not doing schoolwork be a “disease”? There are some societies that do not have formal schooling; how can their children manifest this “disease”? It could not be plainer that these criteria are about the adaptation of a child to society and society’s expectation, not something about the child. If society changed, for example to reward high energy levels, independent thought and creativity, suddenly the “sick” children would be well and the well children would be “sick”. Is this medicine?

Finally, the criteria themselves are ridiculously vague; so vague that they result in the rampant unreliability and discrepancies in the diagnosis. Incredibly, every descriptor in the main category (A) uses the word “often”. What constitutes “often”? Who decides if something is happening “often”? Is 3 times in 6 months often, or 30 times? There are no guidelines, not even an operational definition. It is up to the physician.

Even aside from "often", the rest of the definition is riddled with ambiguous and vague terminology. Which mistakes are "careless" ones? What constitutes being spoken to "directly"? What constitutes "difficulty" in organizing things? Who decides what activities require "sustained mental effort"? What is "easily" distracted? When does a small movement qualify as a "fidget" or a "squirm?" Who determines when "remaining seated is expected?" When is running or climbing or talking "excessive?"

The diagnosis itself, identifying something within the child as the culprit for whatever problems he or she is having at home or at school, is itself destructive. Given the complete subjectivity of the diagnosis, this is a significant concern. In a 1992 report by the Australia Clearinghouse for Youth Studies, many of the participants (individuals working with youth) expressed concern about the destructiveness inherent in labelling a child:

> "The use of terms which focus on the (presumed) aetiology of problems, rather than on the nature of the problems was preferred by some participants. Once again, this appeared to be an attempt to avoid labelling or blaming the young people for their problem."

In relation to the current Draft Clinical Practice Points, we believe that the fundamental flaws of the Draft Australian Guidelines are apparent in the draft Clinical Practice Points. As a result, despite the efforts of the Expert Working Group, the draft Clinical Practice Points are riddled with inconsistencies and must be substantially rewritten. In addition, the Draft NHMRC ADHD Guidelines must be rejected in total.

One of the most alarming statements in the Clinical Practice Points is original and states that "as with any medical intervention, the inability of parents to implement strategies may raise child protection concerns". The dominant medical interventions for "ADHD" are stimulants. The implied threat is that a parent's refusal to allow their child to be drugged with amphetamines or similar drugs may see the intervention of child protection agencies.

The core problem with the CPPs is that the Expert Working Group has failed to deal decisively with the fundamental issue; what is "ADHD" and is it a valid diagnosis? Clearly they are concerned that a clinician diagnosing a child with "ADHD" can't identify what is causing the problem behaviours and therefore has no idea what treatment will match the cause. Yet ultimately they validate the diagnosis of "ADHD" in children.The Expert Working Group has recognised but placed insufficient weight on the absence of systematic, long term, evidence as to the safety and efficacy of "ADHD" medications. Similarly the Expert Working Group has fallen into the traps of;

- dismissing anything that is not a one size fits all treatment even though they acknowledge "ADHD" behaviours have multiple potential causes and
- requiring a higher standard of long term evidence from low risk treatments than that required from invasive inherently high risk treatments.

As it was with the Draft Guidelines, significant evidence of long term harms arising from the use of stimulants has also been overlooked in the CPPs.

While the language of the CPPs is an improvement from the Draft Guidelines, they allow too much discretion based on clinical preference and prejudice. The aim of the CPPs should be to achieve more consistent clinical practice. Unfortunately the current practice of diagnosing and prescribing for "ADHD" is so subjective that a diagnosis of "ADHD" tells us more about the adults (parents, teachers, doctors) in a child's life than it does about the child.

As upsetting as it is to think about any child being drugged with powerful stimulants, it shocks the conscience even more strongly when the child is extremely young. Despite the fact that the "ADHD" drugs have never been approved for use in children under 6, they are routinely prescribed for preschoolers, toddlers and even babies! In Queensland there was one baby prescribed dexamphetamine at 18 months old, and another where the prescription was recommended at 12 months of age. And there is no reason to believe these are aberrations. We have seen how arbitrary, and often absurd, the "ADHD" diagnosis is with any child. But how do you diagnose "inattention" in a 18 month

old? Perhaps the baby was not sufficiently focused on her building blocks. How do you determine when a 12 month old is "hyperactive"? Excessive crawling?

CONCLUSION

Clinicians, educators and researchers sometimes tend to equivocate and "sugar coat" in an effort to sound really "professional". When our children's physical health and emotional well being are in danger, it is time to be very direct. It is time "cut to the chase", look at the facts, and tell the truth.
We are giving powerful and dangerous drugs to Australian children for a "disorder" that has never been shown to exist.

We are allowing Australian preschoolers to be drugged with stimulants despite the fact that they are not recommended for use in children under 6 and no one knows the potential long-term damage. We are allowing such a proliferation of stimulants that it is being sold and shared by Australian children like candy.

We are exposing our children to these dangerous drugs despite evidence that they have no positive effect and only "work" by creating more obedient and docile children.

We are failing to provide parents with meaningful informed consent, and we are failing to give competent children any informed consent in violation of ethical medical practice, the common law and international law.

There is very little that everyone can agree upon in the controversial area of "ADHD", but most would agree that further research needs to be done. At this point there are too many unknowns, and anyone who claims there is "proof" is not telling the truth.

It is bad science to attempt to treat something before we know what it is. Given the acknowledged dangers of stimulant drugs to children, families and society, it is common sense to stop using them until we have identified what, if anything, "ADHD" really is.

Putting the brakes on the runaway "ADHD" train will not be popular with parents, who in large numbers rely on stimulants to control their children and absolve themselves of guilt or responsibility at the same time. It will not be popular with teachers, who rely on stimulants to subdue difficult children in the classroom. It will not be popular with children's physicians, who may not know any other way of being helpful in these situations besides offering stimulant drugs for behavioural control. It will certainly not be popular with the drug companies, who will see any open and honest discussion as a potential threat to their billion dollar golden goose.

This submission is a plea to the National Health and Medical Research Council to take a hard and honest look at a controversial issue. It is a plea to protect our children who cannot protect themselves from these harmful and needless labels and drugs. Finally, it is a plea to celebrate the creativity, spontaneity and energy of childhood and to embrace the unique beauty of every Australian child.

RECOMMENDATIONS

The following three broad recommendations are made in the spirit of protecting the physical health and emotional well-being of Australian children:

1) Declare a moratorium on stimulant use until such time as researchers are able to identify a specific organic etiology for "ADHD", show that stimulants are effective in remediating the discovered pathology and show that stimulants are safe for growing children to use long-term. Alternately, call an immediate moratorium on the use of stimulant drugs in children under 6.

2) Ensure that parents AND children are fully informed of BOTH sides of the “ADHD” debate, and require that they both have to sign meaningful informed consents before receiving any stimulant drugs.
3) Require review by a child guidance professional prior to beginning any child on medication, and require reasonable trials with other suggested interventions prior to initiating the use of stimulant drugs.

The following recommendations relate specifically to the Draft Clinical Practice Points:

Recommendation 1 - The Expert Working Group should recommend that the discredited Draft NHMRC ADHD Guidelines are rejected in total.

Recommendation 2 – The CPPs should state that “ADHD” is not a useful diagnosis and that the term Unexplained Attention and Hyperactive Behaviour Difficulties is a far more accurate description of both the child’s behaviour and the clinicians understanding of its causes. Specifically the term Attention Deficit Hyperactivity Disorder should be abandoned and replaced with Unexplained Attention and Hyperactive Behaviour Difficulties for dysfunctionally inattentive and/or hyperactive/impulsive children when there is no identified cause of their problem behaviours.

Recommendation 3 – The Clinical Practice Points should be rewritten to explicitly reject the American Psychiatric Associations DSM process and state that the ICD-10 diagnostic criteria are to be met in full before a child is diagnosed with Unexplained Attention and Hyperactive Behaviour Difficulties (refer Recommendation 1).

Recommendation 4- The statement that, “as with any medical intervention, the inability of parents to implement strategies may raise child protection concerns” must be removed from the Clinical Practice Points.

Recommendation 5- The statement that, “ADHD also increases the risk of a range of adverse outcomes including educational, social, emotional and behavioural problems during childhood, and subsequent mental health, relationship, occupational, legal, and substance abuse problems in adult life” is equivalent to saying dysfuntional behaviours cause dysfunctional behaviours, and should be removed from the Clinical Practice Points.

Recommendation 6- The proposition that, “developing an effective plan also involves educating the child/adolescent and his or her family and carers about the disorder and its impact on various domains of the child’s life” has the potential to create self fulfilling prophecies of failure for many Australian children and should be removed from the Clinical Practice Points.

Recommendation 7- The CPPs should retain the question “Can pre-school children (under 6 years) be diagnosed with ADHD?” but change the response to ‘NO.

Recommendation 8- The CPPs should include the statement that in line with manufacturers’ recommmendations, medications, including amphetamines and near amphetamines, should not be prescribed for “ADHD” under any circumstances for children younger than six years of age.

Recommendation 9 – The CPPs should include the statement “Clinicians have a responsibility to identify where family dysfunction may be contributing to a child’s inattentive or hyperactive/impulsive behaviour and where appropriate to suggest supportive strategies”.