INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER
BY
CONNECT AND RELATE FOR AUTISM

Connect and Relate for Autism (CARFA) is a national organization that provides Autism services in Victoria and other states. We are a consortium made up of Speech Pathologist, Occupational Therapists, Psychologists, Educators and Autism Specialists. Our primary focus is delivering Relationship Development Intervention (RDI®) which is a parent based developmental approach. We have addressed the terms of reference that are relevant to us as a professional organization.

TERM OF REFERENCE

B). The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services

- At present Services for children with Autism (ASD) and their families discontinue once the Helping Children With Autism funding ceases. This occurs when each child has had his seventh birthday. The $12000 of funding ceases at the child’s 7th birthday regardless of whether funding has been utilized or not.

- Rural areas have decreased choice of services for children with ASD and often long waiting lists for the limited services that are available. To provide an example, a family located in Coronet Bay, Victoria, contacted a consultant from our consortium to explore intervention options for their 7-year-old boy. The consultant enquired if they were newly diagnosed and perhaps had missed out on the opportunity to access the HCWA funding, however the family were not newly diagnosed, they were just unable to access services in their area. The family were able to see an Occupational Therapist who suggested that they use their funding for a trampoline and an ipad, however they were not given the opportunity to use the HCWA funding on the much needed therapy services that their child requires and continues to require beyond his 7th birthday. This is a common occurrence for families who live in remote, rural and country areas where there are very limited services available. For families in this situation, they should be able to continue to access their funding beyond
the child’s 7th birthday so that they have the same opportunity as metro families to make a difference to their child’s life.

- Another example of the difficulties rural and remote families face when attempting to access early intervention comes from one of our RDI consultants, in Mildura, who has had two families from Broken Hill who attempted to access RDI but due to their poor internet connection and being 3 hours from Mildura, by car, the two families ceased intervention. The children were very tired when they arrived at Mildura and families had to stay in Mildura overnight at their own expense to access services. These families do not have HCWA or NDIS services and Mildura is the closest location for them.

C). The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS)

- Relationship Development Intervention is long term remediation addressing developmental disabilities that impact for Quality of Life (employment, relationship). RDI tends to take 1 to 2 years to make significant change. After 1 to 2 years of guidance by the RDI consultant the parent then continues the process independently. RDI is aimed at assisting the person reach their full potential. RDI is taught to the child’s parents and they implement the skills in their everyday life. Many hours of intervention are occurring by the child’s parents without a cost to the parents.

- Older clients, teenagers and adults, with ASD who do not fit into the Early Childhood Intervention age group, require the same long term remediation and intervention as young children, to minimize the devastating impact of ASD. NDIS services for older clients are given as 10 hours for specialized assessment and therapy/intervention.

- NDIS Clients are receiving large funding allocation for support workers to take them into the community so it looks like the client is meeting the “independent” criteria and accessing the community but only minimal hours are allocated for long term remediation intervention like Relationship Development Intervention RDI to address the core issues of ASD that aims to work on the developmental missing steps that impede a person with ASD’s ability to have quality of life.

- There is a very high cost to society in mental health, social welfare and carers requirements when ASD teenagers and Adults are not targeted with specific remediation programs to improve their quality of life outcomes.

- SIX REASONS WHY PEOPLE ON THE SPECTRUM Have Difficulty AS ADULTS:
  - (from Dr. Gutstein’s RDI Parent Workshop)
1. COGNITIVE INFLEXIBILITY:
   A. Absolute, black-and-white thinking
   B. Unable to recognize when something is ‘good-enough’
   C. Unable to adapt as rapidly as circumstances warrant

2. POOR EXECUTIVE FUNCTIONING
   A. Poor at reflection – learning from past experiences (the general principle we learned from making a mistake...not the same as procedural memory)
   B. Poor at anticipating and preparing for potential outcomes
   C. Don’t understand “Murphy’s Law” (don’t assume something will go wrong...if it does, it is catastrophic, the end of the world, etc.)

3. LOSS OF AND/OR LIMITED MOTIVATION TO EXPAND INTO UNKNOWN OR UNCERTAIN AREAS
   A. Avoiding areas of uncertainty
   B. Attempts to control novel situations

4. DAMAGING CONSEQUENCES OF THE ILLNESS
   A. Anxiety and depression
   B. Sense of self as helpless and inadequate
   C. Little perseverance and resilience
   D. Increasingly idiosyncratic thinking patterns

5. DISORDERED EMOTIONAL DEVELOPMENT
   A. Don’t monitor subtle emotional changes
   B. Don’t know how to connect emotional reactions to specific precipitants
   C. Don’t develop effective coping strategies

6. LACK OF PARTICIPATION IN THE NON-RULE-GOVERNED ‘DYNAMIC’ SOCIAL SYSTEMS
   A. Inability to use others’ emotional reactions as a reference point
   B. Unable to function in settings where sharing and integrating new information is the goal
   C. Unable to understand others’ needs if different from one’s own

- Those with Autism, Asperger’s Syndrome and PDD-NOS (the Autism Spectrum Disorders - ASD) do not have a behavioral or social disorder, but a neurologically based information-processing disorder.
- The specific information-processing disorder we call “autism” affects all those on the spectrum and has a profound effect on their internal relationship with themselves and their relationship with others. In turn, this has a devastating effect on their motivations and abilities for friendships, employment and independence, regardless of their IQ, language abilities or academic achievements.
- Autism impacts those on the spectrum in very specific ways: in their motivation and ability to share experiences, co-regulate with others,
integrate their own thoughts, feelings and meaning to create personal memories they can use productively in the future (episodic memory), their ability for self-awareness and appraising ‘best-fits’ between themselves and their environment, and their capacity for flexible, creative thinking and problem-solving. We refer to these as the “core deficits” of ASDs.

- If we are to improve outcomes, treatment needs to specifically target the information-processing deficits. We already know that people on the autism spectrum can learn.
- The question is, can we help them learn the motivations and abilities that will help them succeed in real life outside of school or other institutions? Can we help those with ASD learn the foundational “success skills” that are not measured by IQ tests?
- Many of these success skills we often take for granted in typical individuals: enjoying novelty, being able to cope with uncertainty, “going with the flow,” connecting with others, valuing other’s feelings, ideas and imagination, being flexible, responsive and adaptable, managing and resolving conflicts, seeking out challenges, collaborating with others, taking initiative, being part of a team, assessing situations, seeing the big picture, being resourceful, improvising a solution from what’s available, finding “good enough” solutions, being open to feedback, learning from mistakes, etc. These are just some of the skills needed for friendships, employment and thriving in life.

- One of our consultants has a close working relationship with the Department of health and human services in Victoria and is aware of young adults with ASD whom present with significantly difficult behaviours of concern which require ISP’s of up to $300,000 for independent residential units and day program to provide a 2:1 support ratio. Often the ISP is only being used for the support component of the individual’s needs and an opportunity for therapeutic intervention is overseen due to services managing behaviours at the reactive stage. If more funding was invested earlier with a long term plan, young adults who are significantly impacted by their ASD may have a better opportunity to develop the skills needed to better manage their behaviour, decreasing their support needs. At present, children receive funding for intervention till they are 7. For many families this means that intervention stops and they have to rely on the education system to ‘do a good job’ and hope that when they emerge as adults they will no longer need significant support. Without additional support for families through ongoing access to intervention, this outcome is not likely. It is our hope that the NDIS will address this significant issue and improve funding across the lifespan.

- NDIS planner changing the goals set by specialist, to reduce the number of goals and to link them with the other service professional’s goals, which
the specialist then has to show progress outcomes against goals they did not set.

- NDIS goals are often unrealistic, focusing on skills (eye contact) and short term behavioural objectives. A Developmental emotional relationship model of intervention, supported by new research, is a better option and addresses missing developmental steps and improves the quality of life for each individual with Autism and their families.
- Early Intervention tends to produce progress at a more rapid pace
- Adults in particular may have acquired additional issues of mental health (anxiety,) need longer term view for INTERVENTION.
- What mechanism is in place for NDIS to consider and approve NEW effective approaches? Please refer to research references below supporting emotional relationship based interventions.


D.) Evidence of social and economic cost of failing to provide adequate services

- RDI is long term remediation addressing developmental disabilities that impact for Quality of Life. 1 to 2 years of intervention is often required to make significant changes for the individual’s entire life.
- There is a very high cost to society in mental health, social welfare and carers requirements when ASD teenagers and Adults are not targeted with specific remediation programs to improve their quality of life outcomes.
- Older clients, teenagers and adults, with ASD who do not fit into the Early Childhood Intervention age group, require the same long term remediation and intervention as young children, to minimize the devastating impact of ASD. NDIS services for older clients are given as 10 hours for specialized assessment and therapy/intervention.
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- NDIS planner’s critical role in allocating a selection of services for each case. It is essential that each planner has a thorough non biased understanding of services available to each individual.
- Middle Managers (Case coordinators of services , case coordinators of money, advocates ) are taking money and are not there to provide one to one service to the client.

E). The projected demand for services in Victoria.

- We recommend that Victoria set up a register for people diagnosed with ASD, for purpose of planning ( Note WA register, CP register)
- As of the 16/4/2016 our organisation has 27 HCWA funded children, 47 individuals that are funded privately, 27 individuals that are over 7 years old, 38 children under 7 years old and 17 children that are under 7 years
of age and have exhausted HCWA funding. These statistics are for clients that our organisation services in Victoria only.

Thank you for the opportunity for us to communicate our experiences and viewpoints.

CARFA
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