Government of South Australia
Department for Families and Communities

Disability Services SA

Alternative Care Disability Support Program

A Specialist Service for Foster Families
Caring for children with Disabilities

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Alternative Care Disability Support Program

Who are we?

- The Alternative Care Disability Support Program (ACDSP) is part of **Disability SA's** Specialist Intervention Support Service in Adelaide, South Australia
- Developed to support the unique need of foster carers who are fostering children with disabilities and is funded by the SA Department for Families and Communities.
- ACDSP commenced in April 2005.

Alternative Care Disability Support Program

Children with disabilities in alternative care

- There are approximately 150 children across South Australia in alternative care on a variety of orders who are registered with a disability agency.
- Most of these children have an intellectual disability or global developmental delay and are registered with Disability SA.

Alternative Care Disability Support Program

Rationale

- Children with disabilities under the Guardianship of the Minister have significantly high and complex needs & are at risk for long term emotional and behavioural problems.
- Research indicates children with complex needs in alternative care are more likely to experience multiple placements.(Barber, Delfabbro & Cooper 2001)
- Foster families caring for children with a disability require specialist help due to complex needs associated with the child's disability.

Alternative Care Disability Support Program

Program aims to;

- Prevent placement breakdown.
- Increase knowledge and capacity of foster carers to continue to care for the foster child with a disability.
- Enhance well-being of children and young people with disabilities in foster care.

Primary reason for referral

Behavourial difficulties experienced by foster family, or school.

Alternative Care Disability Support Program

Frameworks used:

- **Developmental**
  Understanding the child's physical, communication, intellectual, social and emotional development.
- **Attachment theory** understanding social and emotional development in children based on children's early attachment experiences.
- **Trauma, Neglect and Grief** impact of these on the child and their overall development.
- **Systems Theory**
  Importance of viewing the child within the wider system and its impact upon the child.

Alternative Care Disability Support Program

- **Eco behavioural approach to challenging behaviour**
  Comprehensive assessment of the child and their environment (home, school, community) and a functional analysis of the presenting behaviour.

Behavioural issues in foster children with disabilities

Few studies prevalence of behavioural/emotional problems in children with disabilities in foster care

Preliminary findings; 100% of children referred to ACDSP scored within clinical range on DBC for emotional and behavioural difficulties.

Existence of intellectual disability/autism compounds behavior and emotional difficulties.

Systemic issues can compound behaviour, school placement, access, respite, frequent changes.

Case Example

- David 10 year old boy with autism and significant intellectual disability
- Failure to thrive substantial neglect by bio mother for first 6 years of his life
- Relatively new foster placement
- Very receptive foster carer but high stress re behaviours

- **Presenting issues**
- **Pica** eating non food items continually (leaves, bark, textas)
- **Constantly searching for food** from floor, bins, dog bowl, leftovers
- "huge" appetite according to carers
- Hyper vigilant around food
- Explosive diarrhoea (variable)

Step 1 Assessment

Developmental Assessment

Cognitive
- Non formal assessment possible
- Adaptive Behaviour Assessment indicated profound deficits functioning at approximately 12 month old level

Communication
- Non verbal Pre-intentional communication level some babbling and vocalizations
- No gesture or signs
- Can attend to people or objects very briefly 2 seconds
- Can touch people of objects to gain attention
- Can follow simple familiar routines

ASSESSMENT

Emotional

DBC (P) indicated scores in the clinical range 93rd percentile for Total Problem Behaviour score

Sensory
- Sensory profile : under sensitivity with vestibular processing = constantly seeking movement

Medical
- Investigations for fructose intolerance. Other tests ruled out reasons for diarrhea. No other medical conditions
- Not overweight & small stature

ASSESSMENT

- **Attachment Relationship**

- Number of previous placements and respite placements
- Removed from previous placement due to inappropriate care
- No access with biological family
- Relatively new foster placement less than 12 months
- Foster parent reports David now responds to her and recognizes her
- Looks to her to have physical needs met
- Foster parent reports major improvements in sleeping and bedtime routine, now tolerates being in bed
- Foster parent highly motivated and receptive to strategies

ASSESSMENT

BEHAVIOUR ASSESSMENT

- **Observations at home, school , OSHC and respite**
- **School**
- Pica reduced at school (inside) limited access to non food items
- School report "obsessed" with food will steal it from others

ASSESSMENT

Observations of Behaviour -Home

- At **home** constantly moving and flicking, mouthing, ie outside leaves and bark,sticks
- extremely high levels of motor activity, seeking of sensory stimulation oral and tactile
- No activities/few toys/no developmentally appropriate sensory experiences for him

ASSESSEMENT

OBSERVATIONS OF BEHAVIOUR

- **Home**
- Foster parent concerned about overeating & diarrhea using low carb food such as fruit /vegetables
- **Play skills** assessed informally with activity sampling. exploratory sensory motor stage, high level self stimulation, flicking spinning,throwing

ASSESSMENT

OBSERVATIONS OF BEHAVIOUR

- At **Out of school care** constantly seeking food scraps, floor, bins,other plates
- OSHC providing very small snacks
- Constant mouthing of toys/ equipment
- No specific activities/toys available
- Constant wandering
- At **respite** little pica observed, access to non edibles very controlled
- Large meal served
- Allowed to play with food whilst eating

ASSESSMENT

OBSERVATIONS Cont.

- Able to differentiate between real food and inedible when provide with both
- Showed increased arousal and anticipation when meals were being prepared, ie jumping, whooping
- If unsure would eat anyway ie sponge from bucket, toadstools

Step 2 Clinical Impressions

- Lack of sensory /gross motor activities hence high levels of motor activity and leaf /bark eating
- Foster parents' first experience of child with autism, unsure what can engage him.
- No knowledge of specialist toys or resources
- OSHC unsuitable for his needs, staff first experiences with child with autism and intellectual disability
- Unsure what to do re food intake 'worried he'll eat till he vomits"

Clinical Impressions

Impact of Neglect on Development

- Failure to thrive and significant level of neglect by bio mother for first 6 years
- Impact of early life experience of neglect access to food, **highly significant**
- Constantly sought food through exploratory means
- Child protection notifications
- High level of oral self stimulation
- Opportunistic mouthing of non food items

Clinical Impressions

Developmental Impact of Neglect

- Prolonged neglect compounded developmental delays unable to tolerate spoon in mouth
- No opportunity to learn use of eating implements
- Led to reliance on finger foods

Clinical Impressions

- Food intake inadequate for physical size and energy level
- Assumptions made re food intake due to disability ie finger foods & toddler size portions
- Healthy diet and food portions i.e. fruit led to sig. less calories
- Long breaks b/w meals

Clinical Impressions

- Unable to verbally request food verbally or gesturally (did so with behaviour)
- Unable to obtain food independently
- Environmental analysis;
- No activities to occupy his lead to constant self stimulation, no sensory based activates or gross motor activities

STEP 3 INTERVENTION

Food Intake

Increased at home esp. carbohydrates up to 2000 cal a day
Frequent snacks & decreased long delays between meals
Increased access to food at home.

Increased repertoire of activities

Activity sampling; play based activities sessions i.e. water play, wide range sensory toys trialled over 8 sessions.

INTERVENTION

Introduction to gross motor activities;
hammock,
swing,
trampoline,

Tactile & visually stimulating items
placed outside ie spinning bells,
wheels & mobiles, spinners and
streamers

INTERVENTION

- Specialized sensory toys such as mirror with bead curtains

INTERVENTION

- Range of sensory toys made available in home environment

ie rattles, shakers

Water based play increased esp outside

INTERVENTION

- Use of Chewy Tubing introduced

  to provide oral motor stimulation and alternative to eating non edibles

INTERVENTION

- Information sessions held with OSHC to assist understand and respond to David's eating
- Examples of equipment and activities suitable demonstrated to OSHC
- Food intake increased at OSHC

INTERVENTION

- Illustrated **personal profile** developed which was distributed to all working with him
- Recommendations made re **specialized toys and equipment** to assist foster carer

OUTCOME

- Foster carer very receptive to all strategies
- Evaluation feedback felt she could now continue to care for him
- Eating non food items at home/ OSHC decreased from continually to very occasionally.
- Chewy tubing significantly decreased indiscriminant mouthing
- Physical environment at home more appropriate and stimulating

Case example

Assessment

- Lack of clarity around his cognitive abilities.
- Assumptions made about expectations re behaviour.
- Marked discrepancy between his behavior at home and at school and respite.
- Extreme distress when required to travel in car
- Query Autism

Intervention

Cognitive and adaptive assessments conducted to clarify his intellectual ability, IQ in moderate range.

Adaptive level around 2-3 year old.

Autism diagnosis confirmed

REFERENCES

Ali, Z .(2001) Pica in people with intellectual disability ; a literature review of aetiology, epidemiology and complications Journal of Intellectual & developmental Disability Vol 26 No2 pp 205 215

Ayoob, K. Kaminer ,R, & Zawel ,J .(1994) Chronic overeating without obesity in children with developmental disabilities; Descriptions of a new syndrome. Mental retardation 32 (3) 194-199

Carter, S. Wheeler, J, Mayton, M (2004) Pica: A review of recent Assessment and Treatment Procedures Education and Training in Developmental Disabilities, 39(4) 346-358

Demb, J.(1991) Reported hyperphagia in foster children Child Abuse and Neglect 15 (1) 77-88

REFERENCES

Mc Adam, D. Sherman, J,.Sheldon, J. Napolitano D, (2004) Behavioural Interventions to reduce Pica in persons with Developmental Disabilities Behaviour Modification vol 28 no 1 45-72

Simms, MD(1989) The Foster care clinic a community program to identify treatment needs of children in foster care. Developmental and Behavioural Pediatrics 10:121-128

Stein, E Rae Grant, N, Ackland, S (1994) Psychiatric disorders of children in care methodology and demographic correlates Canadian Journal of Psychiatry 39: 341-347

Tarren-Sweeney, M.(2006) Patterns of Aberrant eating amongst pre Adolescent Children in Foster Care Journal of Abnormal Child Psychology (34) 623-634