Parents taking charge

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Parents taking charge

Abstract
Presentation made at The Aspect Autism in Education Conference, 31 July - 1 August 2014, Sydney, Australia

Keywords
charge, taking, parents

Disciplines
Education | Social and Behavioral Sciences

Publication Details
Our Stories

• Amanda
• Bernadette
• Todd

• Research and practice
The project

- Data Gathering
- Face-to-face training
- Online support and mentoring
- Evaluation
Our Journey So Far....

• First seminar
• Parent experiences with accessing education programs
• Primary Issues
• Primary Goals
Critical Legislation and Policy

• Disability Discrimination Act of 1992

• Disability Standards for Education of 2005

• Australian Curriculum Assessment and Reporting Authority (ACARA) -
The Australian Curriculum aims to:

- help to ensure all young Australians are equipped with the skills, knowledge and capabilities that provide a foundation for successful and lifelong learning and participation in the Australian community
Catering for the diversity of students

• There is **flexibility** for teachers to shape classroom programs to take into account:
  – the different rates at which students develop
  – the diverse range of learning needs in the class

• Schools and teachers will continue to apply their **professional judgment** about how to best reflect local and regional circumstances, educational philosophies and learning environments
“How can we manipulate the curriculum, adjust the instruction, adapt the environment, and design the assessment to teach and evaluate meaningful outcomes for students with diverse needs”

Principal B Primary
Figure 1. A Model of Differentiation

- Enriched Curriculum
- General Curriculum
- Prioritized Curriculum
- Additional Supports

Lawrence-Brown, 2004
**Academic Systems**

- **Tier III**
  - Individual Students/Very Small Group
  - High Intensity
  - Frequent Progress Monitoring

- **Tier II**
  - Some Students (at-risk)
  - Additional Instruction and Time
  - Small Group Interventions
  - Progress Monitoring

- **Tier I**
  - All Students
  - Universal Screening

**Behavioral Systems**

- **Tier III**
  - Individual Students
  - Intense, Durable Procedures

- **Tier II**
  - Some Students (at-risk)
  - Small Group Interventions

- **Tier I**
  - All Settings
  - All Students
  - Preventive
  - Proactive
Principles of Effective Programs for Children and Adolescents with ASD – Australian Advisory Board on ASD

- Flexible educational service appropriate to individual needs of students with ASD
- Flexibility of educational service that is responsive to students across the ASD spectrum
- Range of educational services
- Flexibility of service to address needs in communication, social skills, learning, sensory issues, and restrictive and repetitive behaviours.
- Flexibility to involve family and students.
- Flexibility of teacher education and training
- Services based on sound evidence and quality indicators.
Empowering Parents to Take Charge

• The DREAM –
  – Parents and children with ASD develop a vision
  – Parents and children conduct an initial assessment
  – Parents and children establish goals
  – Parents, children, schools and professionals work together to establish a plan of action to address the goals within their own domain and evaluate progress
Cycle of Learning

- Assessment
  of Student’s
  Interests, Needs
  and Abilities

- Future
  Vision for
  Student

- Set Goals
  Curriculum and
  Specific Priority
  (IEP)

- Deliver
  Instruction

- Evaluate
  Learning
Cycle of Learning

- Framework for planning and decision making for parents, professionals and individuals with ASD.
- Used at macro level – long term plans/educational plans for individual
- Used at micro level – to plan and evaluate ongoing instruction and programs.
- Should be used by parents/individuals with ASD to develop comprehensive and cohesive focus to achieve long-term outcomes. – decrease fragmentation of programs
Cycle of Learning

Future Vision for Student
Vision Statement

• Includes information gathered from parents, students, and teachers on priorities for learning
• Comprehensive statement that forms the basis of all educational planning
• Establishes the vision for the student for the next few years.
• Establishes the barriers in current and next environment to achieving this vision
• Establishes priorities for goal setting, service and program selection.

• Ultimately should be determined by the individual with ASD – based on person-centred planning.

• Should address key developmental steps faced by student in next few years (i.e. going to school, entering high school, moving out of house).

• .
Over the next few years, our vision is that Harry will move from primary to secondary school, attend inclusive classes for most of the day and participate in extracurricular activities with peers.

• Based on this statement, need to assess Harry’s key characteristics to establish what will serve as an asset/liability to help him achieve this vision.
  • Loves sports
  • Has a good friend at school
  • Wants to attend class with his peers
  • Is a keen reader and loves maths
• Establish key **barriers** to Harry achieving his vision

  • Harry currently has difficulty communicating with his peers and with unfamiliar adults in different settings
  • Harry has trouble with his anxiety and anger in unfamiliar settings
  • Harry has difficulty with writing
• Establish **priorities** for plan and action
  • **Harry**
    • Ways to communicate effectively with peers and adults
    • Emotional regulation skills
    • Self-management skills
    • Skills for written communication
  • **Environment**
    • Learning environment where Harry feels safe
    • Supports communication in a variety of ways
    • Provides differentiated instruction and assessment
1. What is a MAP?
2. The story / background
3. The dream
4. The nightmare
5. Who is the person
6. What are the person’s gifts
7. What does the person need
8. The action plan

MAP can be used when we want to learn from a person’s past to help shape their future.
PATH

1. The dream
2. One year on
3. Now
4. Enrol
5. Growing stronger
6. Actions
7. First steps

PATH is a great tool to use when people feel ‘stuck’ or have a problem to solve.
Cycle of Learning

Future Vision for Student

- Person-centred planning
- Involvement and Self-Determination of Students
- Increases Engagement/Outcomes
- Helps to prioritise key outcomes
Cycle of Learning

Assessment
of Student’s Interests, Needs and Abilities

Future Vision for Student
Assessment is...

• The process of gathering information about a child’s abilities, interests, and challenges for the purpose of making decisions about educational programs and instruction. (Tomlinson, 2005).
How can we assess?

• Informal assessment – Extremely important throughout – Primary means for parents and teachers
  – Checklist
  – Observation
  – Video
• Formal assessment – obtain when and if needed to give specific standardised measure – make sure someone explains implications
  – Cognitive – information processing
  – Academic
  – Adaptive Behaviour
  – Emotional
  – Communication/speech and language
  – Medical
  – Sensory
  – Motor
Characteristics of Autism

- Communication
- Social Reciprocity and Interaction/Relationships
- Repetitive Behaviours & Restricted Interests
- Sensory Issues
- Information processing - Cognitive abilities
- Motor/health needs
Impact Implications
Assets and Liabilities

• What is the impact of this characteristic?
• What are the implications for the person?
• Is it an asset or a liability?
• To what extent?
I'm a learner

What you can do to help me:
I feel like everyone else but I sometimes need a little more help. If you could give me clear and simple instructions and repeat instructions to me that would be really good. Also, I find visual aids very helpful and if you could give me an idea of what we will be learning in the lesson before it starts that will help me get ready for it. Thank you.

Me:
My name is Ayusman but everyone calls me Babu. I am from India and I moved to England when I was 5. I live in Wimbledon with my mum, dad and 3 year old brother, Jackie. I want to be an astronaut when I am older.

Words that describe me best:
very friendly
always cheerful
helpful
kind

Ways ABA support helps me:
Leaving me to do the things I can but helping me when I am stuck.
Helping me in the playground as I find making new friends or understanding new games really hard.
ABA helps explain things in a way that I can understand and learn better.

My strengths and talents:
Numbers and calculations in my head.
My friends in primary school called me Mr Calculator.
I'm also really good at remembering dates and times.
I can remember new facts well.

My favourite things:
My favourite foods are chocolate, rice and vegetables.
I love travelling and visiting new countries.
I love the Guinness book of records and learning new facts.
My favourite subject is Maths.
I like watching shows about Space and nature.
I love going to Theme Parks like Thorpe Park.

My Worst Possible Day:
Traffic making me late for school.
Children being really noisy and misbehaving.
Lots of complex instructions that I don't understand.
No-one to help me get things organised.
Sitting too far from the board so I can't see it.
No-one to play with at lunchtime or not understanding the game.
Getting a detention.

My fears and worries / Things I don't like:
Sudden noises
When things suddenly change
When I don't know what's going to happen next.
When people are late
When people use too much language
I don't eat meat but I eat fish

An Ideal Day:
My escort is on time to take me to school.
The other children don't argue or fight.
The class is quiet for me to listen to my teacher and do my work.
My teacher likes my work.
I play games like chase or be a goalie at lunchtime.
We use maps in Geography.
I have a Numeracy, ICT and Art class.
I earn some House points.
There is fish and rice for lunch.
Me
I am Tessa. I was Born in Broome on 21/11/2001
I have Nyil Nyil and Nykina heritage.
My Aboriginal name is Nyola
My skin is Banaka
My Jarin (life giving baby spirit) is barramundi.

My worst possible day
Days with religion
dress up days, concert days
Lots of verbal instructions
Abstract maths
Teacher making me stand out by helping me
My friends getting in trouble because they helped me.
Not being able to understand what the teacher is telling us and freaking out because I haven’t started

My fears/Things I don’t like
Abstract maths, school, homework, religion
Long wordy instructions without visuals
Anything new that I haven’t done before
New teachers, relief teachers
Partnering up with someone that isn’t a friend
Attention from teachers
Getting in trouble or making a mistake
Teachers that are grumpy or yelling
Unusual school days, like concerts, assemblies, free dress days

What can you do to help me
Make school fun and meaningful.
I don’t want to stand out from the crowd, I want to feel normal.
Try and catch me freaking out before I shut down through fear of not knowing what to do.
Use my friends to help explain things to me.
Teachers freak me out and all I hear is “white noise” when you talk - because I shut down from anxiety.
Always use something visual to explain things
Adjust work when possible to areas of interest

My favorite things
Horses, riding lessons, pony club
Reading novels about horses
Dogs and most animals
Minecraft on computer or x box
Fishing & camping
Learning about Aboriginal culture
My close friends
Anything the colour blue
Broome chicken curry
Balsamic vinegar, warheads

My strengths and talents
I am a good writer
I like reading
I am quite good at concrete maths
I am very good at sports (I like sprinting)
I have lots of great friends
I am good at technology
I know lots about horses
I learn best visually

An ideal day
I look normal. I get to work with a friend.
The teacher explains what we are doing using several different methods (verbally, visually, animations, past examples)
We practice with a friend before we attempt the work alone.
The teacher tells me not to worry about spelling. Timetables & schedules
The maths is meaningful to real life.
No Homework!

Future goals
To get a good education, go to Uni and study business - so that one day I can run my own riding school, horse stud farm and Trial rides
## Planning matrix

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Communication</th>
<th>Social</th>
<th>RI/RB</th>
<th>Sensory &amp; Motor</th>
<th>Information processing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implications</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characteristics</td>
<td>Communication</td>
<td>Social Interaction</td>
<td>Rigid &amp; Repetitive Behaviours</td>
<td>Sensory Processing</td>
<td>Learning Style</td>
</tr>
<tr>
<td>-----------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>-----------------------------</td>
<td>-------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Speaks in 'adult-like' sentences</td>
<td>Limited understanding of social rules</td>
<td>Needs routine</td>
<td>Over sensitive to smells and sounds</td>
<td>Visual learner</td>
<td></td>
</tr>
<tr>
<td>Limited understanding of the language of others</td>
<td>Doesn’t know how to join in with peers</td>
<td>Strong interests in certain subjects</td>
<td>Seeks sensory input for touch/taste</td>
<td>Difficulties with planning</td>
<td></td>
</tr>
<tr>
<td>People over - estimate his comprehension</td>
<td>Difficulty making &amp; keeping friendships</td>
<td>Difficulty coping when unexpected events arise</td>
<td>Avoids certain activities and situations</td>
<td>Can’t remember instructions when given verbally</td>
<td></td>
</tr>
<tr>
<td>Can look like he is being non-compliant, can get into trouble</td>
<td>Peers confuse her attempts to play</td>
<td>Others not interested in their idea of fun</td>
<td>Mouthes inappropriate objects</td>
<td>In wrong place at wrong time with wrong equipment</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Communication</th>
<th>Social Interaction</th>
<th>Rigid &amp; Repetitive Behaviours</th>
<th>Sensory Processing</th>
<th>Learning Style</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep language simple</td>
<td>Explicitly teach hidden social rules</td>
<td>Use interests where possible to motivate or to explain new ideas</td>
<td>Provide a break card</td>
<td>Use checklists and visual reminders</td>
<td></td>
</tr>
<tr>
<td>Give processing time</td>
<td>Provide on the spot reminders</td>
<td>Try to give warning when changes to day occur</td>
<td>Display rules about what is okay to put in mouth</td>
<td>Support instructions visually</td>
<td></td>
</tr>
<tr>
<td>Support language understanding with visuals</td>
<td>Explain to peers how to support their friend</td>
<td>Schedule sensory breaks</td>
<td>Schedule sensory breaks</td>
<td>Use reward systems</td>
<td></td>
</tr>
</tbody>
</table>
Cycle of Learning

Assessment
of Student’s Interests, Needs and Abilities

Future Vision for Student

Set Goals
Curriculum and Specific Priority (IEP)
Work within the Zone of Proximal Development (ZPD)
Why Do We Need to Develop Specific Objectives?

- to clearly state the intended and specific outcome – what will it look like when they have achieved it?
- to improve communication
  - all stakeholders are working towards the same outcome
- to facilitate effective programs and strategies
  - All stakeholders are using data to reflect on effectiveness of strategies and revise where necessary.
- To assist with generalization & maintenance
- To clearly address priorities to achieve individuals’ vision statement.
Goals/Outcome Measures

• Goals should prioritise key objectives and outcomes in academic and/or ASD related areas.
• Goals should be meaningful and accessible for all stakeholders: teachers, parents, students.
• Goals should be functional and focus on the big picture and life skill. – what will be the ultimate skill the individual will need in life?
• Should be based on baseline and “zone of proximal development” for student learning.
Things to remember...

• Should focus on **Big Picture** skill – what is the skill they will use in different contexts across their lifespan?
• Starts with a focus on the **Baseline** – what can he/she do now.
• Should include **Condition** – what resources, support, setting will they need to complete the skill
• Should include **Criterion** – to what degree will they need to demonstrate the skill to achieve it
• Should be clear to all **Stakeholders**, including the children
• Might need to focus on academic and ASD specific (general capability) goals
• Always focus on “what will we **See** him/her **Do**”. 
• Refer back to priorities established for helping the individual achieve the vision.
• How do you establish the individual’s current level of performance in relationship to these priorities?

**BASELINE**

• Priorities for Harry
  • Ways to communicate effectively with peers and adults
  • Emotional regulation skills
  • Self-management skills
  • Skills for written communication
Harry

• **Current Level of Performance – Baseline**
  • When calm, Harry can use short sentences to make requests and answer simple questions. He has difficulty with answering complex questions or describing things or events.
  • Harry can get very anxious quickly when confronted with new people, environments or tasks. He will hum and rock when anxious. He will move easily if within routine.
  • When frustrated, Harry can become angry and engage in behaviours that are moderately destructive such as pushing over a chair, ripping up his work, or stomping away and yelling.
  • Harry can write short text messages on his phone.
Developing Functional Outcomes using V-SMART Goals

- **Vision based** – linked to progress the overall vision of the student.
- **Specific and behavioural** – who? What? Where? Why?
- **Measurable** – how much? How many? How will I know?
- **Attainable** – challenging but doable, realistic
- **Relevant** – worthwhile? Addressing needs? Fits within overall vision? Clear why they need to do it?
- **Timely and time limited** – by when?
Avoid Pitfalls in Writing Objectives

• Objectives should be for the child, not the teacher. Ex: “the student will be provided with opportunities for climbing”.

• Behaviours have to be observable by more than one person. (you can’t observe feelings) Ex: “the student will happily participate in circle time”

• Behaviours and criteria should be specific, not open-ended. Ex: “the student will increase his use of PECs symbols”.

**Parent-Directed Goals**

- **Currently:** Sally experiences anxiety about getting ready for school. She can shower and dress herself, but needs assistance with hair, shoes, and teeth.

- **Goal:** When provided with a visual prompt, Sally will independently get herself ready for school including (showering, dressing, fixing hair, brushing teeth).

- **Currently:** Larry does not initiate greetings or conversations with his grandparents or people outside his immediate family.

- **Goal:** On regular family visits, Luke will initiate a (1) greeting and (2) conversation with both grandparents on 5 out of 5 occasions while demonstrating appropriate use of, and responses to verbal and non-verbal signals.
Cycle of Learning

Assessment
of Student’s Interests, Needs and Abilities

Future Vision for Student

Set Goals
Curriculum and Specific Priority (IEP)

Deliver Instruction
Selecting and Implementing Effective Programs and Strategies

• Selection of program/intervention/service/instructional method should focus on goal/objective and progressing vision of individual.

• Should be based on evidence-based practice

• Should promote generalisation and independence

• Should be linked to big idea – why is it important

• Should link to standard such as curriculum, development, or community
Conceptual Framework of the Evidence-Based Individualized Program for Students With Autism (EBIPSA)

Influences
- Family and student priorities
- Student characteristics
- Current environment
- Future environment

Goals
- Social
- Communication
- Behavior

Process
- Selection of EBP
- EBP implementation
- Outcomes

Model features
- NPDC: Professional development, technical assistance, and support
- APERS: Program quality

Note: EBP = evidence-based practice, NPDC = National Professional Development Center, ASD = APERS
Cycle of Learning

1. **Assessment**
   - of Student’s Interests, Needs and Abilities

2. **Future Vision for Student**

3. **Set Goals**
   - Curriculum and Specific Priority (IEP)

4. **Deliver Instruction**

5. **Evaluate Learning**
Systematic Evaluation: The Critical Factor

• Need for **clear systematic** evaluation of any treatment, intervention, program or strategy.
• Clearly define the intended goal, behaviour change, or physiological change
• Establish a systematic method and timeline for collecting data – try not stay away from reliance on methods based on perception of efficacy
  – Establish a baseline
  – Implement treatment, intervention, program or strategy
  – Collect data
  – Evaluate data at predetermined points in time
Cycle of Learning

Assessment of Student’s Interests, Needs and Abilities

Future Vision for Student

Set Goals Curriculum and Specific Priority (IEP)

Deliver Instruction

Evaluate Learning
Actions parents would like from professionals

* Listen/respect parent input
* Be competent and provide information
* Collaborate and communicate
* Address child’s future
* Develop child’s skills
* Look at “whole child”
* Provide appropriate accommodations
* Follow through

(Prezant and Marshak, 2006)
Advocating for your child

- Know policies and legislation
- Prepare. Be clear about what you want. Write it down.
- Find at least one support person who shares your vision.
- Find out who is responsible or accountable for the decision and action you seek.
- Use proper channels
- Listen to other people’s point of view
- Think about what others may raise and how you might respond.
Advocating for your child

• Don’t always expect conflict but be prepared with a positive strategy if you do strike disagreement.
• Be open-minded; others might suggest solutions that you may not have thought of or different ways of doing things that may be just as effective.
• Try to stay calm, but draw on strong emotion if you need to.
• Ask a friend or professional to help you with advocacy if you need some support.
• (Association for Children with a Disability, 2009) www.acd.org.au
Amanda’s General Tips

• Try the next chain in command
• Be realistic
• Look for attitudes, not specific programs.
• Keep a good sense of humour
• Find the positives in every situation and build from there
• Think outside the box
• NETWORK
• Call for help
THE FUTURE

Life on earth is but a moment caught within the crease of time,
The seasons come and go again,
You have your life, and I have mine.
The seed that's planted within the ground
Cannot choose what to become.
A potato, an apple or a rose for some.
However, for it to be the very best,
It needs rich soil, not poor.
The sun and the rains must come,
To open that seeds door.
I may be born to nourish others,
I may delight the senses.
I may grow tall,
I may grow small,
I may stay stunted beneath wire fences.
My future may not depend on my stock,
So much as it does upon sources.
Sources of warmth, sources of care
I depend on the nurture to be for me there.
Then I can blossom and sing with the birds,
Then I can grow my potential.
So plant me in goodness and all that is fine,
Please keep the intruders away.
Give me a chance to develop, in time,
To become who I am, in life's future, one day!

WENDY LAWSON - http://www.mugsy.org/wendy/asschool.htm
Thanks for Coming

Amanda Webster

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