The UPS

A collaborative approach to assessing and planning support with parents with learning difficulties

Copyright©2019 Dr Margaret Spencer. All rights reserved. Materials cannot be adapted or reproduced in any way without explicit permission of Dr Margaret Spencer School of Education and Social Work, Faculty of Arts and Social Sciences, University of Sydney NSW 2006 Australia. margaret.spencer@sydney.edu.au

A Guide for Users

Contents

The UPS ● Things that affect parenting – Scene 4

Introducing the UPS	2	
Implementing the UPS		
3. The UPS in Practice		
4. How the UPS came to be		
	Helping my child be active aising my child Socialising – belonging and participating	and a second a

1. Introducing the UPS

This Chapter starts by providing a rationale for supporting parents with learning difficulties and the difficulties that exist in translating what we know about supporting parents with learning problems into practice. You will then be introduced to the Understanding and Planning Support Approach (referred to here on in as the UPS - pronounced up(s) as opposed to down) and the novel visual communication tools that support this Approach.

What we know

Research tells us that supporting parents with learning difficulties pays off. In fact the evidence is conclusive – with appropriate support many parents with learning difficulties are capable of meeting their children's needs and enjoying family life together.

Moreover there is now a substantial body of research which details what constitutes appropriate support for this population. We know support for parents with learning difficulties needs to be, among other things, individually tailored and inclusive of the parent's views and goals (Llewellyn, Bye & McConnell 1997).

Translating what we know into practice – the problem

So how do practitioners go about individually tailoring support in such a way that it is inclusive of a parent's views? The simple answer to this question is, to date, not very well.

In the absence of any specifically designed assessment and planning tools, workers when working with parents with learning difficulties, rely on the typical assessment and planning approach they use with parents generally. Workers claim, this typical approach, which requires parents to participate in a process of formulating goals and deciding on the support they require, is difficult to implement with parents with learning difficulties. The reasons given by workers can be summed up under the three themes: We don't know how to talk with these parents; these parents are a "bit of a mystery"; and, these parents can't /don't tell us what they need.

The consequence of this is that far too many families headed by parents with learning difficulties feel alienated in the planning process, fail to receive the support they need, their children are put at risk and irreplaceable familial bonds broken. In short, not getting it right for these family, results in significant emotional social and economic consequences that often times are intergenerational.

Seeking a solution

In response to this practice problem, the University of Sydney and NSW Family Services, with the assistance of an Australian Research Council Strategic Partnership Industry Research and Training Grant, undertook research to develop a specific support needs assessment tool that professionals could use with parents with intellectual disability. This research was led by me, Margaret Spencer, as a doctoral candidate.

The Understanding and Planning Support Assessment and Planning Approach (the UPS)

The outcome of this research was the development of the Understanding and Planning Support Assessment and Planning Approach (the UPS).

What is the UPS?

The UPS is a collaborative approach to understanding and planning support for parents with learning difficulties. The aim of the UPS is to foster constructive and collaborative conversation between workers, parents and others interested in supporting parenting.

The UPS retains the conversational format characteristic of the approach employed by family support practitioners to assess the support needs of mainstream parents and makes this format accessible and meaningful to parents with learning difficulties via a set of visual communication tools.

Four key principles underpinning the UPS

1. It is through talking —exchanging ideas and opinions - that we come to a shared understanding of support needed.

The UPS is based on the belief that knowledge of what is needed by way of support is not something I possess as a practitioner neither it necessarily possessed by the parent. Rather it is in our exchange of ideas – that is, in our conversation – we co-construct what support is most likely to be helpful in this context.

2. "Consensus today keeps dissension away"

This catchy maxim, borrowed from Beukelman and Mirenda (1995), sums up well what we know – that is, if support evolves out of a genuine exchange of views, thoughts and ideas and most importantly makes sense to those who are part of the implementation, supports are more likely be owned, achievable and result in positive outcomes.

3. The problem is the problem not the person

Many of you will be familiar with this maxim from narrative practice (White & Epston, 1990). As Bruce Chalmers (2002) explains by keeping the problem the problem the "heat" is put on the problem, not on any one person. This frees people to externalize problems and explore them with curiosity rather than engaging in personal blame or other damaging practices.

4. Understanding and planning support is a "work in progress"

Family life is dynamic as are their support requirements. How we approach, and the process we use, to assess and plan support needs to reflect this. In other words our assessment and planning of support needs to be seen as a 'work in progress'.

The UPS and the Journey Metaphor

The UPS uses the metaphor of journey. First to describe parenting: that is as an unfolding journey of ups and down, unforeseen obstacles and pleasant surprises. Second to orientate participants as they move through the various stages of the process of discussing, discerning and making decisions about what support will be helpful.

The UPS as a process

It is important to think about the UPS as a process rather than a set of techniques and tools.

The UPS process is divided into three stages.

Stage 1: The parenting journey to date. What's happened? How has it been?

At stage 1 the conversation focus on the parenting journey to date. Toward the end of this conversation the practitioner explores with the parent his or her parenting goals or in other words how she or he would like things to be down the path.

Stage 2: Obstacles on the journey What's getting in the way? What are the obstacles?

At stage 2 the conversation shifts to the current parenting story and the obstacles or the things getting in the way of the parents getting to where they would like to be.

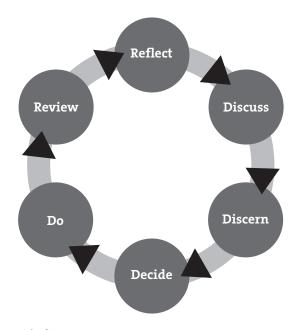
Stage 3: Ways forward. How can things be improved?

At stage 3 the conversation turns to ways forwards: paths to be taken - the advantages of one path over another, the resources needed to head down a particular path and the route to be taken.

It is important to think of the UPS as a spiral process (see diagram below). In other words, it is not meant to be a one off activity but an ongoing part of the casework experience.

The rationale for this is based on the assumption that parenting is a dynamic activity that requires ongoing adjustment to the supports required.

At any time you and the parent can revisit the UPS Map to seek direction regarding where you are at and where you want to be heading in terms of meeting the responsibilities of parenting and achieving personal parenting goals.



The UPS Communication Tools

The UPS as an approach is supported by three visual communication tools.

- 1. The UPS Map
- 2. The UPS Parenting Catalogue
- 3. The UPS Communication Cards

The UPS Map

The UPS Map is the main tool you will use. Like any good map, the purpose of the UPS Map is to guide you through the conversational process of discussing, discerning and deciding upon supports required for parenting.

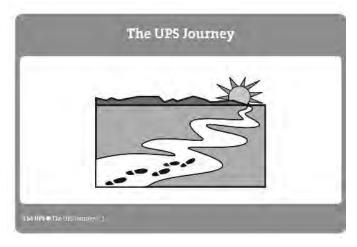
The UPS Map consists of 10 'scenes', visually depicting the different stages of the "conversational journey" you and the parent will take together.

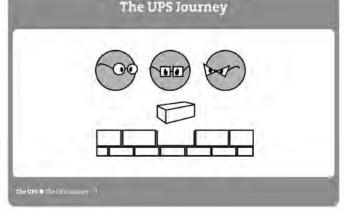
These scenes (as shown on the following pages) can be found in your toolkit as templates that you can photocopy. You record highlights of your conversation on these sheets. Hence this map, as well as guiding the conversation serves as a record of your conversation.



Scene 2: Hitting a brick wall.

On any journey we come up against obstacles – brick walls. Through this scene the parent is encouraged to explore the "bricks" getting in the way of getting ahead with parenting. This scene is used in conjunction with the UPS Parenting Catalogue to explore what areas of parenting are of concern for the parent.



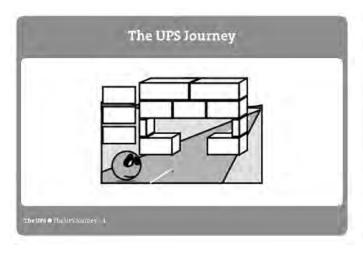


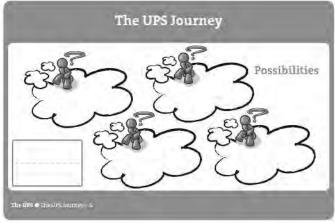
Scene 1: The winding road of the parenting journey.

As the worker you are joining the parent on their parenting journey. You may joining them at the beginning of the journey or meeting them along the way. You will travel some way on the journey with the parent but not all the way (as depicted by the footprints). The purpose of this scene to invite the parent to share with you the parenting journey to date as well as what they see or hope will be on the horizon – that is the parent's aspirations or gaols.

Scene 3: Looking at the "bricks" through different lenses.

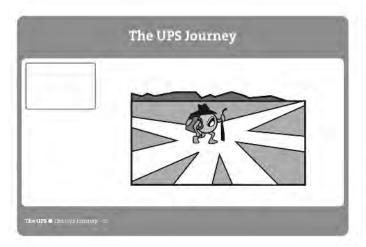
The purpose of this scene is to explore different viewpoints. This scene invites you and the parent to consider how others, for example a significant other or a child protection worker may see or interpret what is getting in the way of parenting.





Scene 4: Selecting bricks to remove.

In this scene the parent is invited to decide on which "bricks" or obstacles he/she wants to work on in order to make a way forward.



Scene 6: Possibilities.

This scene invites you, the parent and others to brainstorm possible interventions, supports strategies for achieving the goal formulated in the previous scene.

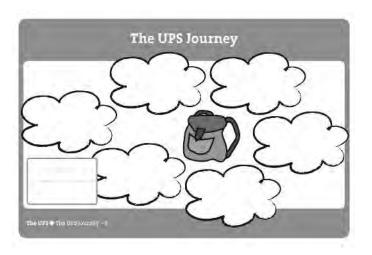


Scene 5: Crossroads.

On any journey we come to crossroads and have to decide which way we want to head. This scene moves the conversation on from discussion about obstacles to setting goals and finding potential ways forward.

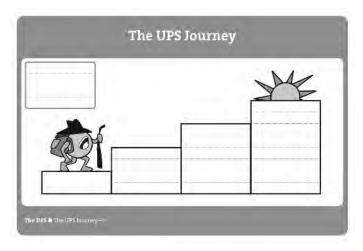
Scene 7: The Pros & Cons.

This scene is used in conjunction with Scene 6 to explores the pros and cons of each possibility.



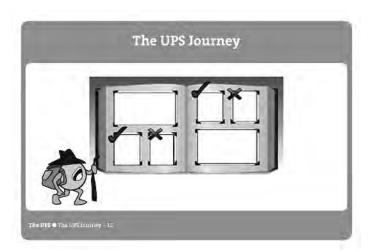
Scene 8: Packing the backpack.

This scene invites you to talk about what resources may need to be put in the backpack for a successful journey as well as "unwanted baggage" that may need to be removed.



Scene 9: The steps to be taken.

This scene serves as an action plan outlining in detail the steps to be taken – by whom, how and when.



Scene 10: How did go?

This scene invites you and parent to reflect and review steps taken.

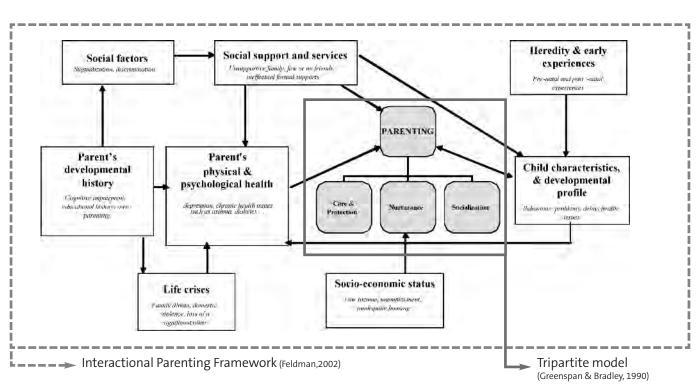
The UPS Parenting Catalogue

The UPS Parenting Catalogue visually depicts 53 items pertaining to parenting.

This novel way of describing parenting came out of watching and talking to people with mild intellectual disability about how they work out what they want or need in other areas of daily living. These individuals indicated that they found pictorial catalogues and brochures helpful in discerning what they wanted. As one parent put it, "that's how I work out what I need...the pictures get me thinking".

The items in the catalogue are based on two conceptual models of parenting. One being Greenspan and Bradley's (1990) Tripartite Model of Parenting and the other being Feldman's (2002) Interactional Parenting Framework.

Greenspan and Bradley's model defines the job of parenting as being threefold - caring and protecting, nurturing, and socializing a child. This conceptual model of parenting was used by Greenspan and Bradley to develop their own support needs assessment tool known as the Parent Needed Support Scale – a comprehensively itemized checklist of the activities of parenting. The limitation of this model however is it depicts the activity of parenting in an unncontextualised manner. To compensate for this we embedded Greenspan and Bradley's model of parenting within Feldman's Interactional Parenting framework. When combined, these two models provide a comprehensive means of thinking about parenting. These two models are shown in the diagram below.



The catalogue is divided into four sections

These are:

- Caring and protecting
- Nurturing "helping my child grow"
- Socialising "belonging and participating"
- Things that affect parenting

The catalogue is used mainly in conjunction with Scene 2 on the UPS Maps during the conversation about obstacles experienced on the parenting journey. The parenting catalogue serves as a visual prompt and helps parents and workers, identify and discuss aspects of parenting and the factors that impact on it.

Each section is colour coded. The following are four samples, one from each of the sections in the catalogue. Note the scale in the right hand corner. This scale helps parents and workers to translate and prioritize concerns on the brick wall Scene 2 UPS Map.

In the front of the catalogue you will find a summary table of all listed items. This summary table can be used to record areas of concern.



The UPS Communication Cards

The communication cards are a set of 35 visual cards depicting feelings, thoughts and concepts that may be relevant and/or may arise in during the conversation.

The purpose of the cards is to help the worker and the parent make 'public' feelings, thoughts and concepts that may be sensitive or emotionally charged and difficult to talk about; or, that are possibly abstract or obscure and need to be explicated and explored.

In the Communication Cark Pack there are:

A set of 15 basic feeling cards.

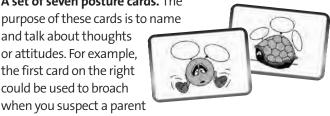
While we acknowledge there are more feelings and emotions than we have included, we have limited the number of



cards to 15 for the ease of use in this pack. To compensate for this, we have included a blank card. The blank card is included so that the worker or parent can record any feeling not in the set.

A set of six response cards. Workers and parents can use these cards to pace communication, express preferences and/or signal mounting frustration, confusion and anger. These cards

are helpful particularly in meeting contexts. A set of seven posture cards. The purpose of these cards is to name and talk about thoughts or attitudes. For example, the first card on the right could be used to broach

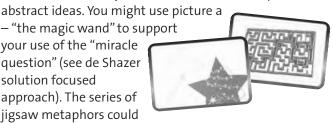


who is saying "yes" but you suspect is thinking "no".

Question: When and how might you use the graphic of the turtle hiding in its shell?

A set of seven metaphor cards. These cards express

– "the magic wand" to support your use of the "miracle question" (see de Shazer solution focused approach). The series of jigsaw metaphors could



be used to explain collaboration or about building a safe family home.

Question: when and how might you use the maze card?

Other helpful communication tools

During the conversational process in addition to the communication tools specifically designed for the UPS, there are 2 other tools you may find useful.

- A sketch book and coloured pens
- The Support Interview Guide

Drawing

Drawing has a number of rewards.

- 1. Is a great way to engage a parent.
- 2. It can lighten the conversational mood.
- 3. Moves the focus on to the story being told on the paper thus making the interaction less intimidating.
- 4. Can assist a parent who is stuck finding words to describe his/her experience.

Tip: You do not need to be able to draw. In fact making your drawing quick, spontaneous and simple will normalize the exercise of drawing, reduce your embarrassment or self consciousness about drawing, and encourage parents to feel okay about utilizing your pens and paper.

TIP: You do not need to be able to draw. In fact making your drawing quick spontaneous and simple will normalize the exercise of drawing, reduce your embarrassment or self consciousness about drawing, and encourage parents to feel okay about utilizing your pens and paper.

The Support Interview Guide

What is it?

The Support Interview Guide (SIG), is a visual tool, developed and trialed over a number of years in numerous research projects undertaken by the Professor Gwynnyth Llewellyn, Associate Professor Dr. David McConnell and the AFDSRC team at the Faculty of Health Sciences, University of Sydney.

The purpose of the SIG is to facilitate conversation between parents and workers about who is there for them and ascertain what these people do, when and how.

Using the SIG within the UPS

It can helpful to use the SIG – that is to explore "who is there for the parent", when and how often, when you are getting a parents to tell you his or her parenting story, also in meeting 3 when exploring how others may see an issue, and again in scene 8 when "re-packing the backpack"

Getting a copy of the Support Interview Guide?

Support Interview Guide is a publicly available document and can be downloaded as a PDF see: www.afdsrc.org.

Summary

- Research tells us that supporting parents with learning difficulties pays off. Effective support for parents with learning difficulties needs to be, among other things, individually tailored and inclusive of the parent's views.
- The UPS is a collaborative approach to understanding and planning support for parents with learning difficulties. The aim of the UPS is to foster constructive and collaborative conversation between workers, parents and others interested in supporting parenting.
- The UPS embraces the same collaborative, strengths-based and family-centred values that underpin best practice in family support work.

4 keys principles underpin the UPS

- 1. It is through talking that we come to a shared understanding of support needed.
- 2. Consensus today keeps dissension away.
- 3. The problem is the problem not the person.
- 4. Understanding and planning support is a "work in progress".
- It is important to think about the UPS as a process rather than a set of techniques and tools.
- The UPS capitalizes on the metaphor of journey.
- The UPS process is divided into three stages.
 - Stage 1: The parenting journey to date. What's happened? How has it been?
 - Stage 2: Obstacles on the journey "What's getting in the way" what are the obstacles?
 - Stage 3: Ways forward How can things be improved?
- The UPS as process is supported by three visual communication tools.
 - 1. The UPS Map
 - 2. The UPS Parenting Catalogue
 - 3. The UPS Communication Cards

2. Implementing the UPS

This chapter will lead you step by step through the process of implementing the UPS

Step 1: Prepare yourself as the worker.

- Before using the UPS it is essential you read the UPS
 Guide and be familiar with the visual communication
 tools. It may help to role play having the UPS
 conversation and using the materials with a colleague
 or friend.
- You will need to photocopy a full copy of the UPS Map (take at least 2 additional sheets of each scene in case you need to write more or make a mistake and wish to start again).
- It is also helpful to include in your tool kit a set of colour pens and an A4 drawing pad.

The UPS Process

As already stated, there are three stages to the UPS process.

Stage 1: The parenting journey to date

Stage 2: Obstacles on the journey

Stage3: Ways forward - How can things be improved?

How long will it take?

The time it will proceed through all three stages UPS will depend on the parent and circumstances.

Some parents will be able to concentrate and be motivated to work through the stages in 1 or 2 long sessions (1-2 hour sessions) While others, will find it harder to focus and need to do the stages over 4-5 sessions (30 minutes -1 hour sessions).

"Where will I find the time?"

In family work, time can be a scarce resource. In such context, spending time talking can be viewed as a luxury. But if you accept that conversation is about knowledge making then talking is not a luxury but a necessity. Furthermore if you weigh up the time you waste not knowing what supports are needed, and implementing plans that are not understood and/or wanted, then the time you take to facilitate a collaborative conversational process which produce support plans that make sense, are owned and doable can only be viewed as time well invested.

Using the UPS: Couples versus individuals

The UPS can be used with parents as a couple or individually.

Ask each parent what they would prefer.

If one partner is more dominant and talks on behalf of the other it is beneficial to do the process with them as individuals and bring them together to share at various points in the process. For example you may bring them together after they have individually identified the obstacles (scene 2) to have a conversation about the concerns. Also you may first brainstorm possibilities (scenes 6) individually and then discern possibilities (scene 7) with them as a couple.

UPS meeting schedule

It is suggested, you schedule on average four meetings or "times to talk".

Meeting 1:	Introducing parent to the process and materials.
Meeting 2: date.	Talking about the parenting journey to
Meeting 3:	Discussing the obstacles or challenges to parenting.
Meeting 4:	Planning how things could be improved or made different.

Meeting 1: Inviting and preparing the parent

The purpose of this meeting is to prepare the parent or parents to participate in the UPS process.

Start by explaining the aim and purpose the UPS. For example,

"(Name) I would like to organise some time that you and I can work out together what is going to be helpful support for you for parenting. I don't have the answers and I don't expect you to have them either but together we can work out what support makes sense and is doable and helpful for you and your family".

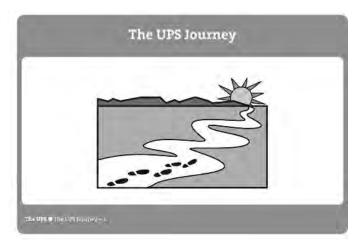
Show the parent the UPS communication tools and explain how you used them..

Negotiate the best place and time to use the UPS.

If you intend using it in the family home, discuss with the parent what would be the best place to use the materials for example sitting on the lounge or around the kitchen table. Alternatively a parent may be able to engage more effectively in the process if you meet at your centre.

Meeting 2: The parenting journey so far

The purpose of this meeting is to invite the parent to tell you their parenting journey to date and to ascertain what are their aspirations, hopes and goals for themselves and their children.



Scene 1 is a graphic of a long winding road.

Start the conversation by talking about parenting as a journey. Invite the parent to tell their parenting journey so far.

"Tell me how things have been? Tell me about when you become a parent? What has happened along the way."

After the parent has done this refer back to Scene 1. Explain to the parent that you are going to walk with them on the journey for a while (point to the set of footprints).

TIP: It is helpful to plot this story a blank piece of paper. Draw a time line (like a road) across the page. From the left hand side of the page and going across record critical and/or significant events. You do not need to be Picasso—stick figures are fine. (See page 15)

Direct the parents attention to the sun on the horizon and ask the parent about what are his/her hopes, goals as a parent and record above the sun.

TIP: Sometime parents with learning difficulties can have trouble with the abstract concept of goals. Alternatively you may ask the question:

"In two years time what would you like to be happening for you as a parent and for your family."

At the end of meeting 2, introduce the UPS Parenting Catalogue. You might want to leave the catalogue with the parent and ask them to browse through it prior to when you meet again. Invite them to rate each item using the scale in the bottom right hand corner. Alternatively you can get them to put post tags on the pages they think relate to their parenting circumstance.

TIP: If you are concerned that the catalogue may get lost or gauge that the parent would benefit from going through it with you, just introduce them to the catalogue and explain this is you with me talking with them about during your next meeting.

Meeting 3: Discussing the obstacles or challenges to parenting (scenes 2-4)

The purpose of this meeting is to explore and reflect upon concerns and obstacles for parenting.

Explain the scene in the following way:

"Along the journey we come up against brick walls — obstacles — that can stop us doing what we want to do or getting to where we want to go. What aspects of parenting do you have concerns or you find problematic?"

Invite the parent to go through the UPS Parenting Catalogue and identify items they views as being of concern or problematic

Record the area of concern to the brick wall adding 1-3 x's to denote level of concern.

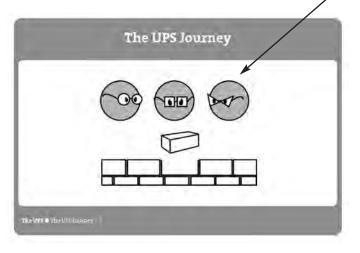


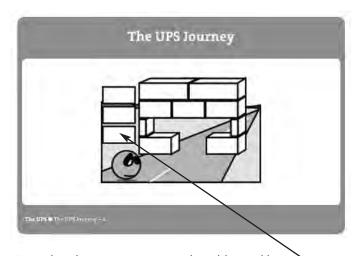
The purpose of this scene is to facilitate critical reflection and discussion about what other interpretations may exist around an issue.

Questions you could ask

"Other people may look at this concern differently. Who might these people be? What may (name) say about this concern?"

Record different interpretations above each framed face.





Record each concern or area to be addressed here. The bricks moved to the side represent the area of concerns the parent and you decide to address.

Questions you may ask

If we are to make a pathway through, which areas of concern should be and remove or address?

What makes this an important concern/issue for you to address now?

Tip: In order to keep the task of planning achievable and not too overwhelming, it is recommended to deal with only three issues at any one time. Write the 3 issues in the boxes to the side

At the end of meeting 3 you and the parent have:

- Identified areas of parenting which are of concern.
- Explored why they are of concern.
- How the concern is interpreted by others (for example a significant other or a teacher or a child protection worker).
- Decided which concerns will be addressed at this point in time

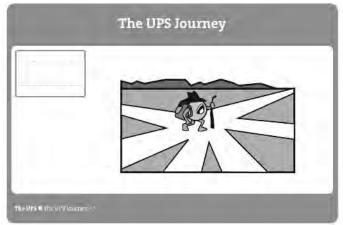
Record this goal on all subsequent sheets related to addressing this concern.

TIP: To assist parent construct a goal, encourage them to consider, as you did with scene 1, how life would be, what would be happening if in 6 months you had moved on from this concern? That is if this concern was no longer a concern.

Meeting 4: Planning support

The purpose of this meeting is to come up with a plan that the parent, you and others can own and believe is realistic and doable.

Take one concern at a time and follow through the process from scene 5-9.

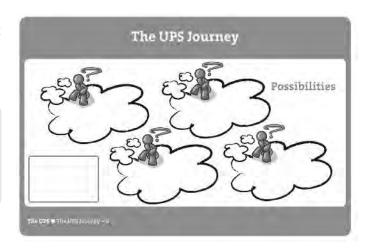


Start the meeting by showing the parent scene 5 - a journeyer at a crossroad.

Explain:

"We are now at a crossroads. There are many ways we can go, now I would like us to think about the best way to move ahead and address this concern."

In the box in the (L) hand corner record the parent's goal, for example: If the parents concern is about feeling isolated, the goal may be, "to feel part of a supportive community".



This is a scene of possibility clouds. The aim of this scene is to brainstorm ideas or possibilities for achieving your goal (recorded in box).

Start by asking the parent what they think might help. You and the parent may agree to invite others into the conversation at this point. If you decide to do this make sure you first brainstorm with the parent. Moreover avoid making this a "worker dominated" gathering as this will usurp the power and voice of the parent.

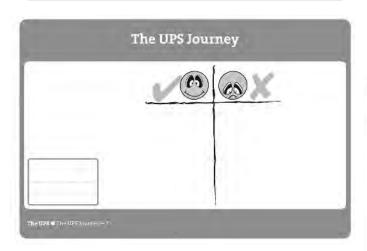
TIPS: prior to this meeting ask the parent to think of things that could be helpful.

Remind the parent that at this stage all ideas, no matter how seemingly silly or unachievable, are worth floating.

Avoid jumping in too quickly with your ideas. Make your suggestions only after the parent has exhausted their list of ideas. When you do put forward a possibility do so tentatively.

You might invite others to contribute here in various ways. For example, invite other service providers to submit suggestions. You may introduce new ideas or possibilities via brochures or resources you bring along to show the parent. Once again share these suggestions only after the parent has exhausted sharing their ideas and not as things the parent must comply with or agree to. Write each idea on different clouds.

Last, avoid problem solving or elaborating on any one idea at this point in time. This will happen when you do the pros and cons of each possibility.



The purpose of this scene is to test how realistic and feasible the suggestions are and to help decide which is the best suggestion.

After brainstorming all possibilities, use this sheet to weigh up the pros and cons of each suggestion.

Ask the questions:

What are the pros and cons or positives and negatives of this idea?

Is it a doable idea?

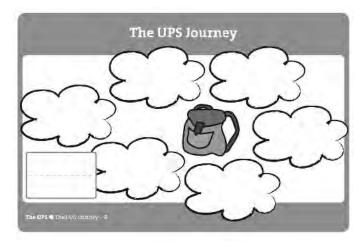
Is it going to help us achieve what we want?

How will we do this?

What else might we need to do?

TIP: Photocopy a multiple copies of this sheet and use a new sheet for each possibility.

What you will find is that ideas may be combined or adapted through this conversation process. In summery, what you and the parent come up with will be co-constructed.

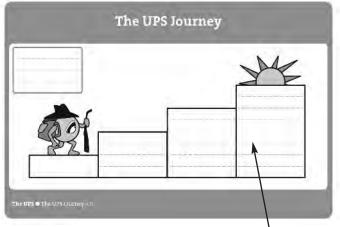


The purpose of this scene is to explore the resources that might be needed to make the possibilities a reality.

Ask the question:

"On any journey it is good to work out what we want to take out or put in our backpack before we set out."

TIP: resources may be in the form of people, materials, finances or emotional resources that might be called upon or for that matter taken out for example: anger, pessimism or negativity).



Scene 9 serves as your action plan.

Record steps to be taken by filling out each step. Make each step concrete concise and specific.

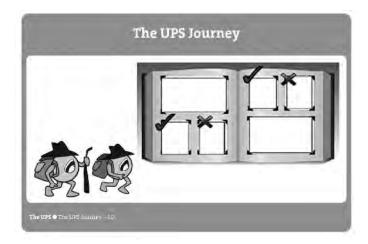
For example: Step 1 (parent) will ring child care centre on Monday when (worker is doing regular home visit) and arrange a time to meet with (teacher). Step 2: (worker and parent) will attend meeting and ask for help to deal with (child's behaviour); step 3 (worker and parent) meet three afternoons a week for two weeks to learn and practice the behavioural strategy with (child).

The question you will ask here is

What are the steps we need to take?

TIP: make sure steps are concrete and specific.

Meeting 5: Re-visiting the plan



The purpose of the last scene in the UPS Map is to facilitate review of the support plan

This conversation occurs after the plan has been implemented.

Ask Questions such as:

"How did it go? What worked well? What not so well? What would you like to do again? What do we need to do now?

Following this discussion you and the parent may decide to embark on another journey. You can do this by finding an appropriate place in the journey process to re-enter. This may be at the brick wall or the cross roads or repacking the backpack.

Summary

- On average the UPS can be implemented over four meetings. This of course will depend on the parent's concentration and circumstances.
- It is better to take the time to talk with a parent in a constructive way than waste time implementing interventions that are not understood or wanted.
- The UPS is not an approach that you can not do 'on the run'. Be prepared before visiting the parent. Also prepare the parent prior to each meeting.
- Remember the purpose of the communication tools is to facilitate constructive conversation for the purpose of coming up with a support plan that is owned and doable.
- Finally the UPS is a work in progress. It is a living document that can be used and reused through the journey you take with the parent.

3. The UPS in practice

This chapter provides a case example how the UPS approach was used with Kasey, a mother with learning difficulties. In this chapter you will also find some helpful hints for communicating effectively with parents with learning difficulties and fostering collaborative conversation.

Background:

Kasey has two daughters – 3 year old Heather and 7 month old Lulu. She and the children live in the one bedroom public housing flat. Kasey is separated from Terry, her de facto, who she claims drinks, bullies and intimidates her. The Domestic Violence Liaison Officer with the local police command made a report to the Child Protection Authority. After visiting the family, Child Protection referred Kasey to the local family support centre. Kasey's case is given to Marley – a family caseworker. The referral from Child Protection raises concerns about the family home being very untidy and suggests Kasey's needs help with creating a safer home environment for the children.

Meeting 1: Preparing to use the UPS with Kasey

Marley meets with Kasey in the family unit. Marley spends some time putting Kasey at ease. At the same time Marley is gauging Kasey's apprehension and openness as well as how she responds to questions.

Marley also explains what her service does and collects intake information required. After a while Marley invites Kasey to participate in a series of conversations to discuss, think about and decide **together** what support is going to best help her parent her daughters.

Marley emphasizes this is something that she needs Kasey help with; that she doesn't have the answer as to what is going to work best for Kasey and her daughters, and, neither does she expect Kasey to have the answers but believes that by talking together, they can work it out.

Marley then says that she has a kit to help Kasey and herself talk and work out what is required. She then shows the materials to Kasey. Explaining how the materials will be used.

Marley asks Kasey if it was okay that they make some dates to meet to do the UPS.

They decide to have these talks at Marley's office over the next two weeks. This allows Kasey to take advantage of the free child care offered each morning at the centre.

Meeting 2: The Parenting Journey

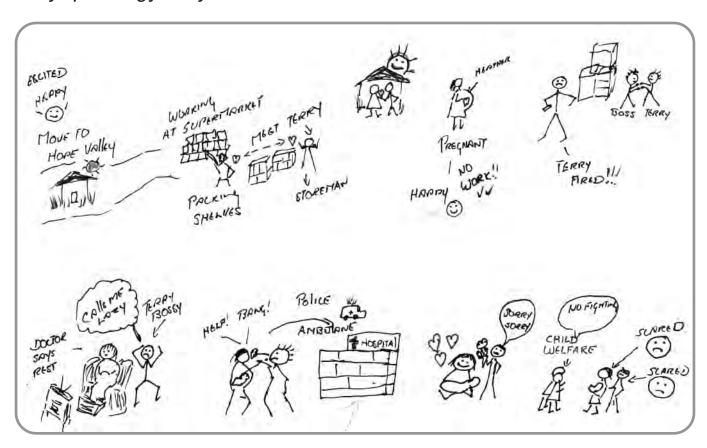
Marley decides to meet with Kasey in a room used for counselling. There is a lounge, a coffee table and a table and chairs to the side. In preparation she has photocopied the UPS Map, has on hand a sketch book and colours pens and has sorted the communication cards in piles (see using the communication cards).

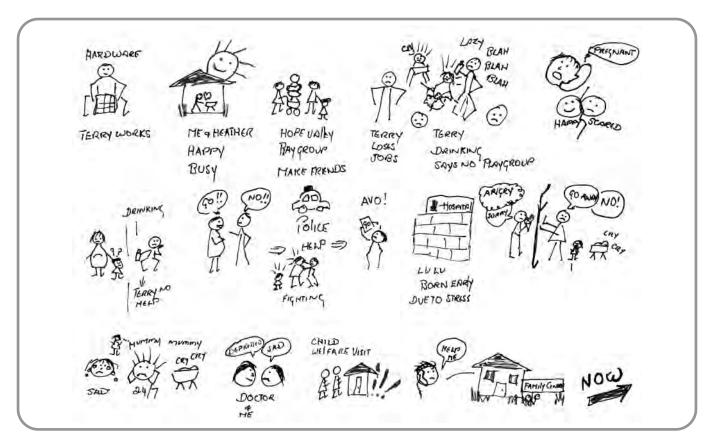
Kasey arrives and settles the children with the child care worker. Marley invites her to come to the counselling room and gives Kasey the option of sitting the table or on the lounge. Kasey and Marley decide to sit at the table so they can spread out the UPS materials. Marley sits beside Kasey so they are both able to look at the materials. Marley reminds Kasey about the aim of their conversation reiterating the this is something that they have to work on together.

She also talks more specifically about the aim of today's meeting. Marley talks about parenting as a journey and puts in the centre of the table scene 1 of the UPS Map. Pointing to the maps Marley explains that she hopes to walk with Kasey for a while helping her reach her goals. But before moving ahead she would be interested to hear from Kasey what the parenting journey has been like so far and to hear what has happened? She helps Kasey start telling her story by saying" so Kasey, Heather is now ...?" Kasey jumps in and says three last March. "Marley responds "So you were ..." "I was 22 years old and living in the unit I am in now ...the unit that I got when I came out of care." Invite Kasey to narrate her parenting journey. She introduces this by asking "Kasey tell me when you became a mum and what has happened since?"

Marley suggests they map out Kasey's story on a blank piece of paper. Kasey says she can't draw and Marley says neither can she but find drawing things helps her see and remember key things.

Kasey's parenting journey to date





TIP: It is helpful to draw the parenting story in the style of a comic strip as in the example above.

TIP: For the purpose of this exercise you do not need to be Leonardo Di Vinci! Stick figures, lines and simple words are fine. In fact the less perfect your drawing the more willing the parent will be to add to your drawing or in some cases take over as the drawer as well as being the story teller.

Reflection Questions

What do you see as the point of getting Kasey to tell her story and for that story to be recorded visually? What are your thoughts/reactions about this way of finding out the parenting story? How do you feel about drawing?

Note how Marley talks about drawing as something helpful for herself as the worker. How do you think this helps? If you were Marley how and when may you have used the communication cards during this conversation?

After drawing Kasey's parenting story

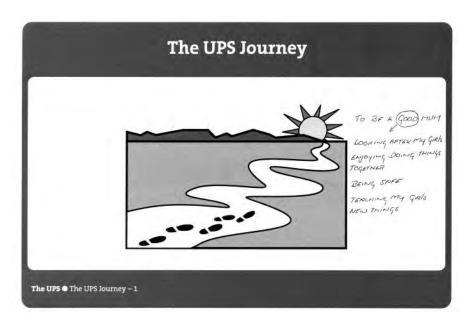
Marley reintroduces Scene 1. "if we are here now and you were to look to the horizon (points to the horizon) how would you like things to be or to look like after we have worked together for a while?

At first Kasey simply says "to be a good mum". Marley echoes this statements "to be a good mum?" This prompts Kasey to explain what she means by being "a good mum".

End of meeting 2

Before bringing the meeting to a close Marley shows Kasey what she would like to talk about next time they meet. She shows her the brick wall and the UPS Parenting Catalogue. Kasey asks if she can take the catalogue home and promises to bring it back.

Kasey asks if she can keep a copy of her story. You organize to photocopy it for her. You put it in a folder and suggest Kasey bring it back to your next meeting and if she likes she can decorate the folder.



TIPS: In the pilot study, some parents liked to keep a copy of their UPS materials. They would keep the pages in a manila folders. Some parents decorated and personalized their folders. Workers assisted by taking digital photos of the parents, the child and family pets etc, which they gave to the parent to put on their folder. Workers believed this activity helped the parents engage with the process and to take ownership of the end plans.

Meeting 3: Obstacles on the journey

Marley prepares for this meeting as she did for the previous one.

Marley starts the meeting asking Kasey if she had any thoughts since last meeting. Kasey eagerly reports that she has been through the parenting catalogue and circled things that were concerns.

Marley suggests they put these concerns on to the brick wall. After doing so they discuss each concern at length. Marley asks questions such as what makes this a concern, how does this impact on you and on the children. She also gets Kasey to rate her concerns.

At the end of this process the brick wall is as depicted below.

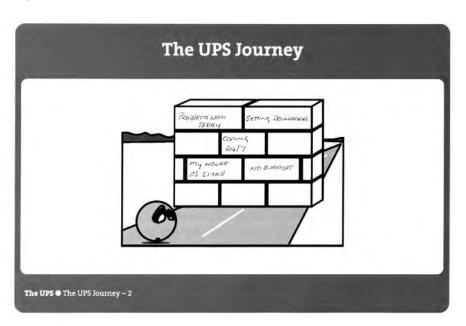
Marley and Kasey spend time talking about each brick and exploring connections between bricks.

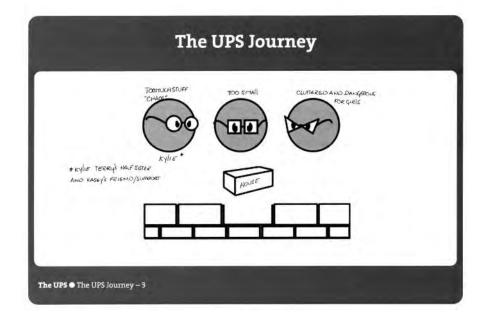
For example, Marley asked Kasey what might be the connection between your depression and coping with everything 24/7? Kasey sees the link and adds I think because the unit is so small and things are everywhere it is really hard to cope ...also I am always uptight that Terry is hanging around.

Marley is aware that the child protection workers were concerned about the state of the unit stating there were safety issues for the children. Kasey has listed "keeping the house tidy as a concern" but has not raised "home safety" as a concern.

Marley invites Kasey to tell her more about the untidiness. Kasey complains that the unit is so small and that Heather is forever making a mess. Marley uses the next scene to explore the issue of tidiness and child protection's key concern about home safety.

She also invites Kasey to interpret how someone else – she chooses Terry's sister who Kasey nominates as a friend – views/understands the untidiness.





If you were Marley what may be some helpful strategies you may use to diffuse potential defensive posturing, maintain collaborative relations and strive towards a shared understanding?

Marley invites Kasey to reflect on other peoples' interpretations of the untidiness problem. Note how Marley externalises the problem.

TIPS:

- Externalize problems. Make the problem the problem not the person.
- Describe rather than defend your position or understanding.
- "Help me understand?". Adopt a not knowing stance. Assume you are the one is having trouble understanding.
 Invite the parent to help you understand from his/her perspective.
- Allow the parent to describe rather defend his/her position. Do this by being genuinely willing to hear parent perspective without jumping into critique, judgment or argument.

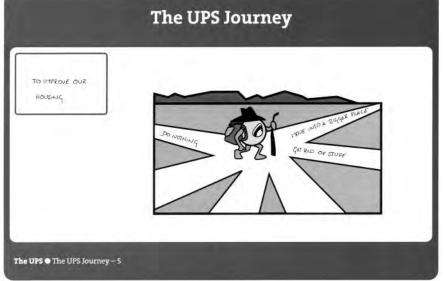
Marley asks Kasey to choose three concerns or bricks she would like to work on. Marley explores with Kasey her choices. Marley is genuinely interested to find out why she has chosen these and why they are important to Kasey.

TIP: Some parents with learning difficulties say things to please. At this stage in the conversation if you sense the parent choosing concerns that they presume will keep other people happy, explore this possibility using the communication cards such as these below.

End of meeting 3

Marley thanks Kasey for helping her understand how things are. Marley affirms Kasey's preparedness to talk as well as her desire to be a good mum. She also reminds Kasey she does not have to fix things on her own or have all the answers but that together they can work on the identified concerns. She introduces Kasey to the next step in the process by showing her scene 5, saying "now we are at a crossroads. See there are different paths we could take to resolve these concerns. Lets look at your top concern the one about housing." Kasey and Marley explore some possible paths (see next scene).





TIP: See how Kasey places being back with Terry as a backward path? When exploring the direction with the parent, ask where they would like to position that direction, for example backwards, sideways or straight ahead.

Before drawing the conversation to a close Marley sets some homework for herself and for Kasey. She suggests that before they meet next week she and Kasey separately think of possibilities for addressing the concern nominated by Kasey as her first priority, that being, to improve the family's housing.

Meeting 4: Planning support

In preparation for this meeting Marley makes a few phone calls to see what other services could offer Kasey and her children.

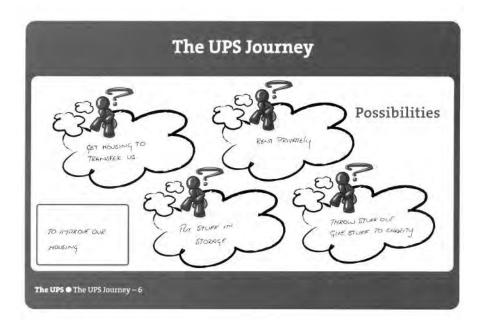
As at previous meetings, Marley lays the UPS Map out on the table.

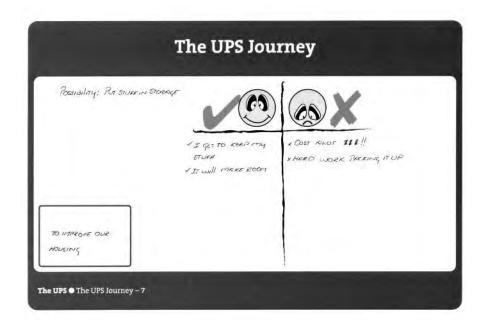
Kasey arrives at this meeting with paperwork for the local housing authority, some brochures about storage and some private rental listings. For Marley this is a positive sign that Kasey is engaged in the process and motivated to address her concern about the family's current housing situation.

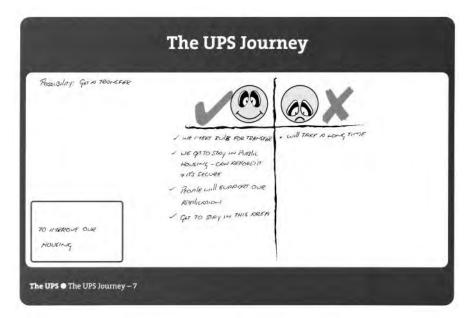
Marley invites Kasey to remind her where they are up to in the process and where they are up to on the UPS Map. Marley allows Kasey to share what she sees as possibilities. She affirms each idea as valid and avoids displaying any negative or positive reaction to each idea.

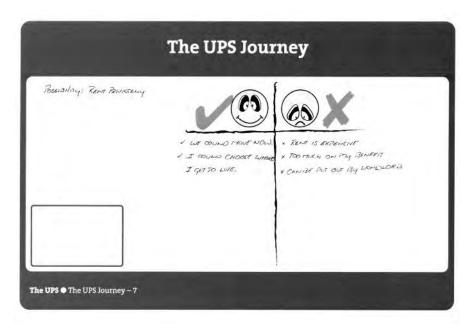
After recording Kasey's ideas, Marley suggests she and Kasey explore the pros and cons of each idea.

TIP: For this session have at least four additional copies of the scenes 6, 7,8 and 9.





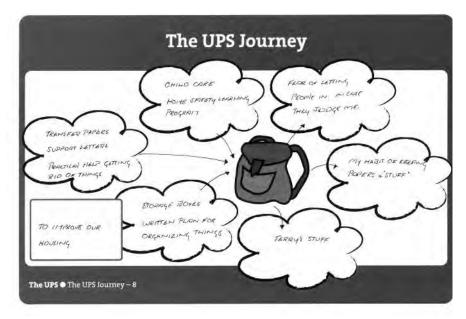




Through the process of exploring the pros and the cons Kasey and Marley come to a shared and clearer understanding about what is going to be most helpful and realistic.

What questions might you ask to test helpfulness and whether or not the suggestion is realistic?

Marley introduces scene 8. and says, "On any journey we need resources. With this scene let's explore what things we need to put in our backpack and what things we may need to take out". At this point in the conversation Marley provides Kasey with information about resources that are available. She puts these out as possibilities but not as something that Kasey has to accept.

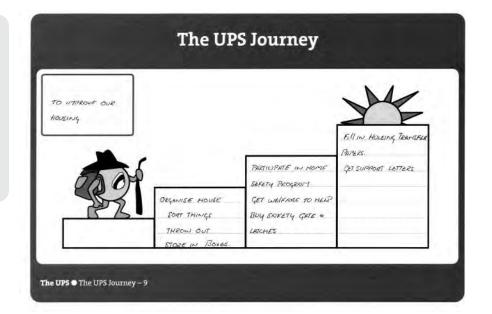


TIP: Think creatively about what comes out as well as what goes in the backpack – things that come out or go in may be practical things, a human resource, an attitude or stance or emotion.

Having repacked the backpack, it is now time for Marley and Kasey to work out the steps they are going to take. Plan three steps at a time. The plan is likely to be doable and you and the parent have a sense of making gains (even if they are small in the big schema!)

TIP: When filling out scene 9 record each steps simply, concisely, and concretely. Ask questions what will we do? Who will do it? When will it be done by?

You might like to explore with the parent what will be different when the three steps have been achieved. Write these difference up near the sun.



Getting to this point

At this point you now have what is equivalent to an action plan.

In most cases, due to time and the energy the process demands, you and a parent will only be able to address one concern at a time in meeting 4. This being the case, you may need to repeat the meeting 4 process on more than one occasion.

TIP: It is better to work on fewer concerns and experience success than to over plan and set up unrealistic expectations for the parent and yourself as a worker.

Reminder: The UPS is a work in progress. You can revisit any stage of the journey when appropriate. For example you may find you need to review the Map to remind a parent why you are working on a strategy or have a conversation that explore how or why you have hit a brick wall or dead end.

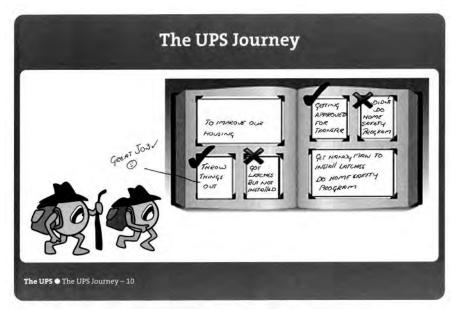
What about scene 10?

Scene 10 is used to review the action plan – to review whether we did what we said we would; what worked, what didn't, and why; and where to from here?

Marley arranges a meeting with Kasey eight weeks after they have drawn up their plan to address Kasey's goal – to improve her family's housing situation.

In preparation for this meeting Marley sets out the completed UPS Map. She invites Kasey to help tell the story about how they drew up the Map.

Marley then introduces scene 10 and invites Kasey to talk about how things have been? What worked? What didn't work as expected? What else needs to happen? From this conversation, Marley and Kasey draw up a new set of steps to bring them closer to the goal of improving the family's housing situation or decide this goal is complete and move on to a new concern.



Where to from here?

Having read the last three chapters you will be familiar with UPS as an approach to understanding and planning support as well as the communication tools provided to help you and parents with learning difficulties engage in constructive and collaborative conversation about what support is needed for parenting.

At this point, the best way to learn more about the UPS is to take it out and use it with a parent. Good luck!

The last chapter in this Guide is an overview of the research undertaken to develop the UPS. Following the next chapter you will find a reference list and some interesting and useful websites.

4. How the UPS came to be?

For some time now, mainstream family support agencies in Australia and overseas have reported a growing number of parents with learning difficulties coming to their services for support. These are parents who meet the formal diagnostic criteria for intellectual disability (that is a IQ <70 as well as limitations in at least two adaptive behaviour skills) as well those who self identify or are classified by service providers as having learning difficulties (these individuals tend to have IQs in the borderline to low average range). While people with learning difficulties is not a new phenomenon, their increased 'visibility' is attributed changes in disability policy and practices which recognize the full citizenship rights of people with learning difficulties to live 'ordinary lives' in the community and to form intimate and sexual relationships (Booth & Booth, 1994; Sigurjonsdottir, Trausdottir, & Johnson, 2000; Tymchuk, 1999) While a minority of parents with learning difficulties will struggle to meet the demands of parenting, research demonstrate that the majority, particularly if provided with the timely and adequate support, do just fine.

Supporting parents with learning difficulties

Generally speaking, what parents with learning difficulties need by way of support is not really different from what all parents need: parents with learning difficulties, like any other parents in the community, need support to secure basics things such as housing and adequate finances, practical help with things such as child minding and transport, support to learn and develop parenting skills; support to ensure their own health and wellbeing is maintained, support to meet and make friends with other parents, help to participate in the community, and emotional support from family, friends and loved ones. The problem for parents with learning difficulties is that

The problem for parents with learning difficulties is that more often than not their ability to access and negotiate such support is denied them. Consequently families in which one or both parents have learning difficulties are at high risk of falling apart. The moral, emotional and economic costs on children, parents and the community as a whole are unconscionable. Particularly when in many cases, with enough good will and careful planning, it need not be the case.

What we know works

Research tells us that supporting parents with learning difficulties pays off. In fact the evidence is conclusive - with appropriate support many parents with learning difficulties are capable of meeting their children's needs and enjoying family life together.

Moreover there is now a substantial body of research which details what constitutes appropriate support for this population. Over the past 30 years researchers and practitioners here in Australia and overseas, have invested much time and energy into finding out what works by way of support for these families. For example support for parents with learning difficulties is most effective when it;

- Is responsive to the practical concerns confronting the parent and family
- Is respectful and inclusive of the parents' views and feelings
- Is attentive to ecological factors which may affect parenting (for example, a parent's health and well being, physical, social and economic circumstances, the number, age and health of the children cared for)
- Is proactive and preventative in its orientation
- Is flexible over the long term in order to respond to the family's changing needs
- Builds on individual, family and community strengths
- Fosters self esteem and competencies
- Employs learning strategies that are specific, structured, situational and sensitive;
- Helps parents engage with and negotiate "the System"

These points are endorsed by parents with learning difficulties themselves who, in recent years, have made an important contribution to the discourse about what helps (Booth & Booth, 2003; Strike & McConnell, 2002; Tarleton & Ward, 2007). In short what parents say they want is support that;

- Respects and incorporates their views
- Accommodates but also looks beyond their 'disability' label
- Recognizes and builds on their competencies
- Is delivered as promised
- Is non-judgmental and empathetic
- Addresses practical issues

Putting what we know into practice

McConnell (2008) contends that "equity demands that governments and human service agencies translate these findings from research into policy and practice to support parents with learning difficulties and their children" (p. 7 italics replace terminology used in text).

Since the early 1990s NSW Family Services, the peak body for family support programs in New South Wales in partnership with Professor Gwynnyth Llewellyn, her research colleagues in the Faculty of Health Sciences at the University of Sydney have worked collaboratively to identify factors affecting access and availability of support to parents with learning difficulties from mainstream family support services (see Llewellyn, 1994; Llewellyn & Brigden, 1995; Llewellyn, Bye & McConnell, 1997)

An obstacle for practice

Llewellyn, Bye and McConnell (1997) looked at the support and service needs of parents with learning difficulties from three perspectives – that of parents with learning difficulties, their significant others and professionals involved with the family. What this study highlighted was the three parties had differing views and priorities vis-à-vis support.

In their conclusion, Llewellyn, Bye and McConnell (1997) recommended:

"mainstream services incorporate an individualized service planning approach in their work with parents with intellectual disability"; and that "services need to incorporate procedures into their service planning which involve parents in selecting and setting personal parenting objectives" (p. 76)

The question arose: how were workers to translate these recommendations into practice? In the absence of any specifically designed assessment and planning tools, workers when working with parents with learning difficulties, relied on the typical assessment and planning approach they use with parents generally. Workers claimed, this typical approach, which requires parents to participate in a process of formulating goals and deciding on the support they require, was difficult to implement with parents with learning difficulties. The reasons given by workers can be summed up under the three themes: We don't know how to talk with these parents; these parents are a "bit of a mystery"; and, these parents can't /don't tell us what they need.

Seeking a solution

To address this problem, NSW Family Services and the University of Sydney successfully applied for an Australian Research Council Strategies Partnership with Industry Research and Training (ARC-SPIRT) Grant.

The objective of this research was to conceptualize an assessment and planning approach and translate this approach into a practical format family support workers could use in their everyday casework with parents with learning difficulties to assess and plan support.

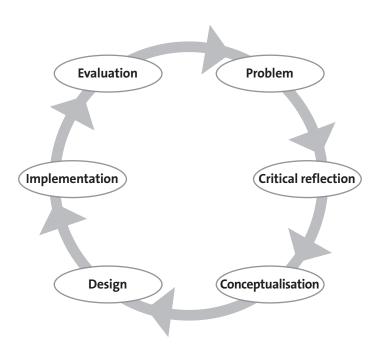
The Research Project

This project was undertaken as a reflexive inquiry. Reflexive inquiry is a research method that fits within the genre of action research. Its aim is to raise self awareness and critique taken for granted practice in order to generate new knowledge and improve practice. Reflexive inquiry cycle phases of reflection – action – reflection (see figure 1)

The research approach chosen was influenced by both the nature of the research task as well as my own background as the person invited to conduct this research. I came to this research project not as a "track-record researcher" but a as someone with 20 years experience working with at the coal face with individuals and families where one or both parents have learning difficulties and in the last decade training and mentoring family support workers working with parents with learning difficulties.

The Inquiry Process

The reflexive inquiry, in keeping with the nature of this form of research, evolved over a number of phases (see figure 1).



The problem

The first phase of my inquiry involved developing an in depth understanding the problem. This led me to talk expensively to frontline workers. Workers reported, in the absence of having any other way, they employ this typical approach in their work with parents with learning difficulties. When asked how this worked the consensus was that it was problematic with a number of workers going as far as to say "it does not work". Three themes emerged about the difficulties workers encountered. These were: workers' feeling out of their depth in knowing how to communicate appropriately with these parents; uncertainty on the part of the workers knowing what parents with learning difficulties know and don't know; and line of inquiry was to talk with frontline family support workers.

Critical reflection

My next line of inquiry was to explore how this problem has been addressed to date. My review of the literature revealed that to date the assessment of the support needs of parents with learning difficulties has been via assessment of their skills and capacity - an approach in keeping with a diagnostic/treatment framework.

I then turned to my own assessment practice making this a subject for research. To assist me in the reflexive process I solicited the help of a "critical friend" an experienced colleague whose role it was "to ask questions and making tentative suggestions to unseat previous perceptions, to find other possibilities and insight" (Taylor & White, 2005 p. 64). I came to understand that essentially my approach to assessing and planning support with parents with learning difficulties was in keeping with the typical approach employed by workers: However I identified a few other things I had in my "assessment tool kit" that gave me "the edge" when it came to working with parents with learning difficulties. These included: I held optimistic, and such as countercultural, beliefs in the capacity of parents with learning difficulties, I was comfortable with and had strategies I employed to facilitate communication strategies, I had an analytical template I employed, somewhat tacitly, to organize my assessment and planning support and I had a wealth of practice knowledge and by virtue of my official role as a specialist consultant on parenting with learning difficulties an authoritative status which gave a credibility to my assessment

I convene a validation group to share my findings and to seek feedback and advice about how to progress in our objective of developing an assessment tool workers could use to assess and plan support with parents with learning difficulties. The validation group comprised seven expert practitioners whom I personally invited and whom had extensive knowledge and experience in the family support sector. The advice by the members of the validation group was as follows: whatever was to be developed should be aligned to family support principles – that is, put succinctly it should be strengths-based. Secondly, anything technocratic would be unacceptable to workers and possibly also to parents; in other words, the assessment of support should not be turned into a checklist of activities. Finally whatever I developed should be kept conversational and relationship-based – that is, the thing the frontline workers I interviewed reported they found most difficult to do with parents with learning difficulties.

Conceptualization

At this stage of the inquiry I return to my own assessment practice with my reflective gaze drawn to the function of conversation in the assessment process. Being able to converse with parents with learning difficulties seemed to be critical to coming to know their support needs. This led to the realm of epistemology, a branch of philosophy which explores knowledge making, and in particular to social constructionist theory I came to understand the assessment of support needs from a social constructionist perspective and developed conceptual framework on which to structure approach assessment.

Design

The next phase of inquiry involved translating this conceptualization of assessment as a collaborative and dialogical process into a practical 'tool' that workers could use in their work with parents with learning difficulties.

The end result of this was development of the UPS - a collaborative conversation approach supported by a set a set of creative visual communication tools. These tools were developed based on invaluable advice provided by parents and people with learning difficulties. Implementation

The UPS was trialled by 20 family support workers in New South Wales. These workers participated in a face-to-face orientation and information session, given some background reading and other relevant literature, given the UPS materials and asked to use it as much as possible in their everyday case practice with parents with learning difficulties over a six month period. During this period workers also had access to an on-line list serve discussion forum and telephone support.

Evaluation

At the end of the implementation phase data was collected from all participants. Data was collected through face to face interviews, collection of de-identified UPS materials (for example completed UPS Maps) and two participant forums. The data was thematically analysed.

Findings

The findings were positive. Workers who used the UPS demonstrated that it had utility, that is, it served its purpose of facilitating collaborative conversation between workers and parents with learning difficulties in order to come to a shared understanding about support and plan for implementation.

Some workers who participated in the trial used the UPS successfully with parents with whom they had an existing case work relationship. Their feedback is particularly noteworthy. Here is what some of them had to say,

It opened up conversation ... far more ... than I could have ever imagined. They [the parents] really got into the tools. I tended to sit back and they would respond to the pictures before I had to say anything. I wasn't instigating the conversation ... they were ... The journey metaphor clicked for them... It was their horizon and their brick wall. They were making the decisions about what direction they wanted it to go ... yes, I was on board doing my share of the work, making suggestions and asking questions to get them thinking, but they were steering the ship.

It brought us together. It was a concrete activity we worked on together around the kitchen table. It gave purpose and structure to our meeting ... and it was an activity that got the parents involved ...the plan we came up with in the end was a team effort; they definitely had greater ownership of the plan... I know this because they are following up on tasks.

The UPS gave her [the mother] a voice to tell her story ... let her say what she wanted to say without people putting words in her mouth. Using the visuals, she was able to say "yes that's me, that's how I'm feeling ... that's the issues and this is what I want".

It was like working with a different woman. Instead of my visits being a drag, things started to happen: I could talk to her and she could talk back. I got more from her in one session using the tools than I had in 6 months.

There is a very clear visible difference in the parents after using the UPS compared to past methods. The parents are more engaged, they seem to have more confidence and ownership, the plan in place now...they feel they own it.

Working from this approach changed things. Once she knew that what she was saying, I was hearing and taking on board, she became animated in her conversation ...

Before, she would just look into the distance and not be present. Before, I could see her disconnecting and she would give out only what she assumed we wanted to hear. I was lucky if I got more than yes/no answers. But [using the UPS] there was a real animation and that is how I knew it was working ... we were getting through to each other.

The findings also draw attention to some contextual issues that could potentially limit the UPS being used generally by family support workers in their everyday practice. One of these is current work practices and pressures. For some workers taking time to plan and/or do anything different was perceived as a luxury not afforded them in their busy work schedules. Whether using the UPS with its collaborative conversational approach does in fact take more time or would be more time efficient in the long run needs further investigation.

Another issue that could potentially limit the UPS being used generally is the systemic culture which impacts family support workers' everyday practice. In the findings two cultural factors were identified. The first relates to the ingrained pessimistic and prejudicial attitudes about parents with learning difficulties. The other is the system's tokenism to genuine collaboration with parents as well as its preoccupation with "fixing the family up". Further research is required to investigate ways of overcoming these obstacles.

Furthermore, the scope of this research was limited to looking at the workers experience of using the UPS. In order to improve this resource it would be important that research be undertaken to gather first hand parents' perception of having their support needs negotiated using the UPS. Moreover it would be helpful to research the familial and environmental factors that affect the effective implantation of the UPS in order to understand with which families and in what context the UPS is going to be most useful.

Conclusion:

The UPS is a response to an everyday practice problem — that is family workers difficulty assessing and planning support with and for parents with learning difficulties. As an approach it remains faithful to the values of espoused by family support workers of working in an empowering, collaborative and strengths based approach, making these values accessible in casework practice with parents with learning difficulties. A trial of the UPS in everyday practice has been positive. The challenge now is to make the UPS widely available, user-friendly for workers and not just another tool kit that sits on a shelf to collect dust. The UPS is now in the process of being published by NSW Family Services and will be available to the human service sector later in 2009.

References

Anderson, H. (1997). Conversation, language, and possibilities: A postmodern approach to therapy. New York: Basic Books. Aunos, M., & Feldman, M.A. (2002) Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research and Intellectual Disabilities*. 15 (4), 285-296.

Beukelman, D., & Mirenda, P. (1995) Augmentative and Alternative Communication. Baltimore MD: Brookes Publishing Co.

Booth, T., & Booth, W. (1994a). Parenting under pressure: Mothers and fathers with learning difficulties. Buckingham: Open University Press.

Booth, T., Booth W., & McConnell, D. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Applied Research and Intellectual Disabilities*. 18, 7-17.

Booth, T., & Booth, W. (2003). In the frame: Photo-voice and mothers with learning difficulties. *Disability & Society*, 18(4), 431-442.

Budd, K. S., & Greenspan, S. (1984). Mentally retarded mothers. In E. A. Blechman (Ed.), *Behaviour modification with women* (pp. 477-506). New York: The Guildford Press.

Chalmer, B. (2001). *Collaborative assessment: An alternative to psychological evaluation*. Retrieved May 22, 2002, from www.somewareinvt.com/vcca/collab_assess_paper.doc

Edgerton, R. B. (1967). *The cloak of competence*. Berkeley, CA: University of California Press.

Greenspan, S, & Bradley, K. (1990) Supporting parents with mental retardation in the community. Paper presented American Association of Mental Retardation Conference October 1st, Providence RI.

Hayman, R. L. (1990). Presumptions of justice: Law, politics, and the mentally retarded parent. *Harvard Law Review*, 103, 1201-1271.

Llewellyn, G. (1994b). Generic family support services: Are parents with learning disability catered for? *Mental Handicap Research*, 7(1), 1-14.

Llewellyn, G., & Brigden, D. (1995). First hand experience: Parents with learning difficulties. *Disability, Pregnancy & Parenthood International*, 11(July), 10-12.

Llewellyn, G., McConnell, D., & Bye, R. (1998). Perception of service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities*, 19(3), 245-260.

McConnell, D. (2008) *Position Paper* Special Interest Research Group, IASSID.

McConnell, D., Llewellyn, G., & Ferronato, L. (2000). *Parents with a disability and the NSW Children's Court*. Sydney: The Law Foundation of NSW & the Family Support & Services Project, The University of Sydney.

Sirgurjonsdottir, H. B., & Traustadottir, R. (2000). Motherhood, family and community life. In R. Traustadottir & K. Johnson (Eds.), *Women with intellectual disabilities: Finding a place in the world* (pp. 253-270). London: Jessica Kingsley.

Tymchuk, A.J., Llewellyn, G. & Feldman, M.A. (1999) parenting by persons with intellectual disabilities: A timely international perspective. *Journal of intellectual & Developmental Disabilities* 24(1) 3-6

Strike, R., & McConnell, D. (2002). Look at me, listen to me, I have something important to say. *Sexuality and Disability*, 20(1), 53-63. Tarleton, B. & Ward, L. (2007) Parenting with Support: The view and experiences of parents with learning disabilities. *Journal of Policy and Practice in Intellectual Disabilities*. 4(3), 194-202

Walter, J. L., & Peller, J. E. (2000). Recreating brief therapy: Preferences and possibilities. New York: W. W. Norton.

Walton-Allen, N. G., & Feldman, M. A. (1991). Perception of service needs by parents who are mentally retarded and their social service workers. *Comprehensive Mental Health Care*, 1, 137-147.

White, M., & Epston, D. (1990). *Narrative means therapeutic ends*. New York: W. W. Norton.

Williams, V. (1999) *Creating effective visual metaphors*. Paper available on

www.personal.psu.edu/staff/v/q/vqw/Portfolio/VislMeta.pdf

Helpful Websites

On parents with learning difficulties

http://www.healthystart.net.au

http://www.parentingrc.org.au

http://www.afdsrc.org

http://www.famservices.asn.au

http://www.bristol.ac.uk/norahfry/right-support/

http://www.cornwall.nhs.uk/specialparentingservices

On collaborative practice

http://www.harlene.org

http://www.taoinstitute.net

http://www.somewareinvt.com/vcca/coassessment.htm

On narrative practice

http://www.narrativepractice.com

http:www.dulwichcentre.com.au

Plain English & Visual Communication

http://www.plainenglish.co.uk/guides.htm

http://www.plainenglishfoundation.com/

http://www.bild.org.uk

http://www.inspiredservices.org.uk

http://www.changepeople.co.uk

