# BE-KIN

# CO-DESIGNING EARLY CHILDHOOD EARLY INTERVENTION (E(EI)



THERE ARE VARIOUS CHALLENGES CURRENTLY BEING EXPERIENCED BY FAMILIES AND PRACTITIONERS IN THE IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME'S (NDIS), EARLY CHILDHOOD EARLY INTERVENTION (ECEI) PROGRAM FOR YOUNG CHILDREN WITH A DEVELOPMENTAL DELAY OR DISABILITY, AND THEIR FAMILIES.

THIS PARTICIPATORY DESIGN AND RESEARCH PROJECT WAS CONDUCTED IN PARTNERSHIP WITH BROTHERHOOD OF ST. LAURENCE. IT INVOLVED THIRTEEN TWO-HOUR FACE—TO-FACE AND ONLINE WORKSHOPS WITH ELEVEN FAMILY MEMBERS OF CHILDREN WHO USE THE ECEI PROGRAM FROM BAYSIDE PENINSULA AREA, VICTORIA, BETWEEN OCTOBER 2019 AND JUNE 2020. TOGETHER, WE CO-CREATED TOOLS THAT CAN FACILITATE POSITIVE EXPERIENCES IN THE NDIS ECEI SUPPORT NEEDS ASSESSMENT AND GOAL-SETTING PROCESSES. THIS FILE CONTAINS BE-KIN (ORIGINALLY BEACON), ONE OF THE TOOLS DESIGNED TO BE USED EASILY & REFLEXIVELY BY DIFFERENT PEOPLE (E.G. ALONE. WITHIN FAMILY OR WITH TRUSTED OTHERS) AT DIFFERENT POINTS OF THEIR NDIS JOURNEY.

TEAM: JAZ HEE-JEONG CHOI, MUTSUMI KARASAKI & GENEVIEVE LAMB
CONTACT: CARE-FULL DESIGN LAB (HTTPS://www.rmit.edu.au/care-full) for more information



# THERE ARE THREE TYPES OF CARDS IN BE-KIN:

# IDEAS SPAGHETTI



Showing prompts for reflection, with coloured corners for connecting ideas.



Showing tools you can use to engage in handson activities, see next page for Circle of Care Card Instructions.



Showing excerpts from the stories different Beacon Family members.

Some cards are blank or have blank spaces where you can draw or write down your thoughts and questions. If you'd like you can also jot down your ideas on the back of the cards. And of course, you can also use these cards simply as postcards.

# HOW TO USE THE BE-KIN CARDS

Each card reflects different needs, wants, hopes and dreams for you, your child, family, and kins in your NDIS journey together. These prompts were co-designed with a group of families who have used the NDIS ECEI, who generously shared their experiences, thoughts and feelings, in the hope of helping others who are starting or already on their own NDIS journeys. While the idea for the cards was being developed, the families fondly referred to them as "the beacon"; so we refer to the family, with same fondness, the "Beacon Family." You can read more about the Beacon Family's NDIS journeys on the Stories cards.



These cards can be used in many ways. For example, you may use them in the days/weeks before a meeting with your ECEI Coordinator to think about things to ask or tell them. You may even want to bring them with you to the ECEI meeting, so that you don't forget things you want to talk about with the coordinator.

There are no rules to how you use these cards. You can pile them up facing down and flip one card at a time, or start by laying them all out facing up. They can be used on your own, or with other family members or people who are significant in your child's life. If appropriate, you can also involve your child(ren)! What's important is to keep in mind that these cards are best used playfully (like a fun card game) and respectfully (of everyone who's involved - so we refer to them as 'Players') to think about and co-create your NDIS journeys together with care. We have provided some suggestions on how to play, but it is completely up to you how you play them, so feel free to make up your own rules.





# PLAYING WITH CORNERS





# Grouping corners:

Can you group the cards into themes?

Create your own categories and sub-categories. Examples of themes include: practical help and support; life journeys (Short-, mid- and long-term); creating support networks; areas of transformation for you, your child and/ or your family. You also cluster cards within the same theme by connecting their corners with a matching colour.



# Players' corners:

You can use the corners to represent each player - e.g:
Player 1 places a card on a larger sheet of paper. Other players then write down thoughts around their assigned

Player 1 places a card. Each of the other players select a card in response to the previous player and connects it using their assigned coloured corner.

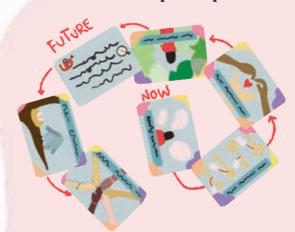
coloured corner.

Future Spiral spread:

PLAYING WITH IDEAS SPAGHETTI (ARDS

Each card's corners are coloured purple, yellow, pink and orange. You can use these coloured

corners to connect cards, like in the game Dominoes. Or, you might choose to place the cards in a particular spread as a way of guided storytelling or story sharing. Either way, it may help to take some time to explore the cards first, and put aside any that do not resonate. Here are some ideas to get you started, but we're sure that as you play with them more, you'll discover new ways to play that suit you best.



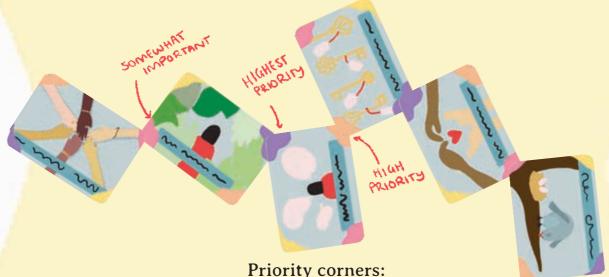
Start from the middle of the spiral, describing a current situation, and continue your way outwards, describing what the future could hold.

# PLAYING WITH SPREADS

# Hopes & Fears spread:



Place the cards in a cross shape like in the diagram above, to detail your current situation. What makes it challenging? What are your hopes and fears? Is there a way forward?

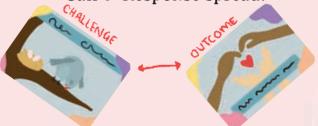


You can use the corners to reflect on and express priorities. Each coloured corner can represent the level of priority for the issue illustrated on the card (e.g. Purple for highest priority; Orange for high priority; Pink for somewhat important; Yellow for least important). For instance, Player 1 places a card and Player 2 "connects" their card in response to Player 1's card using the purple corners, indicatinging a high priority response to Player 1's card. Players can discuss this connection then continue to build on the cards using the corners as priorities.

# Timeline spread: NEAR FUTURE

Draw a timeline and place the cards on it.
Use each of them to describe your situation in the past, present, near future (e.g. within the next 12 months), and long-term future (years from now). Change the tense of the prompts if necessary.

# Call & Response spread:



Lay the cards out in pairs, with the left card representing a challenge your child, you or any kin/s may be experiencing, and the right card representing an ideal outcome, or potential response to help improve the situation.



# HOW TO USE THE CIRCLE OF CARE CARD



Use this card to think about people, services, and groups that are important in your child's, your, your family members', and kins' lives, when it comes to raising the child on an NDIS journey. The circle used in this activity is modeled on the diagram about the ECEI approach that can be found in a booklet called Early Child Early Intervention, published by the NDIS (please see Page 3 of the booklet). Each 'slice' of the circle represents different areas, or domains of life. In the original booklet, these domains are: 'Family and friends', 'Education', 'Health', 'Community', and 'NDIS'. You may use these life domains, or can choose to use areas of life that resonate with you better, like we have done in the example diagrams below.



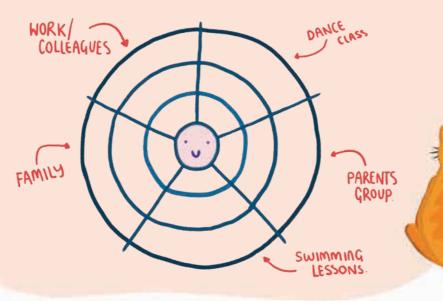


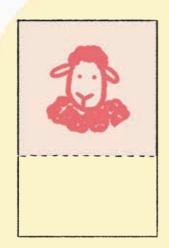


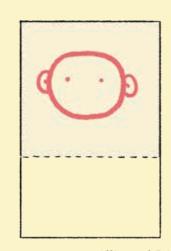


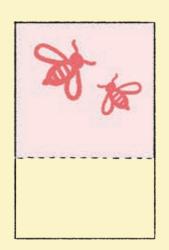
Who Am I tokens

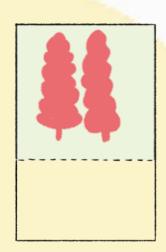
Draw the circle on a larger piece of paper. Cut out the 'Who am I' tokens and place one on the centre circle. This represents the central person (CP) in question for the activity. It could be you, your child, or anyone significant to you and/or the child. Think about different important areas of the CP's life. For example, these might be kinder/childcare, family and friends, and playgroup for your child. For you, it might include your work, social circles, or your child's activities that you attend. Write down the names of these life domain areas on the paper.





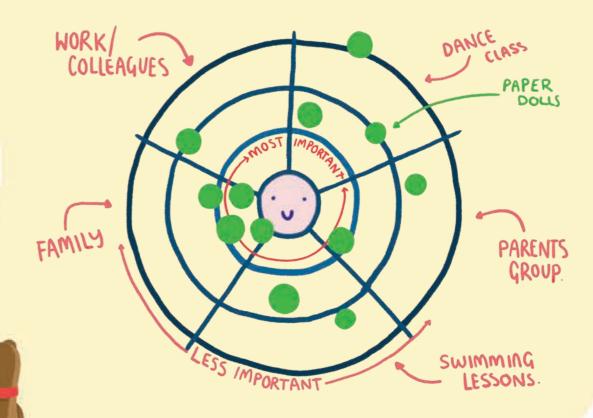




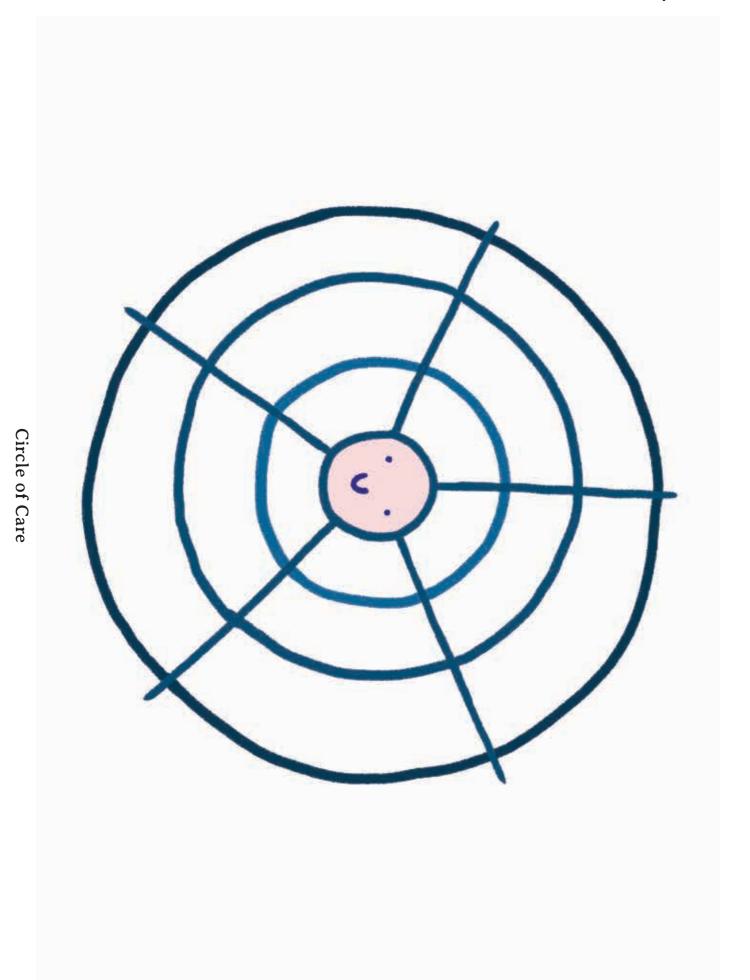


Allies and Friends paper dolls

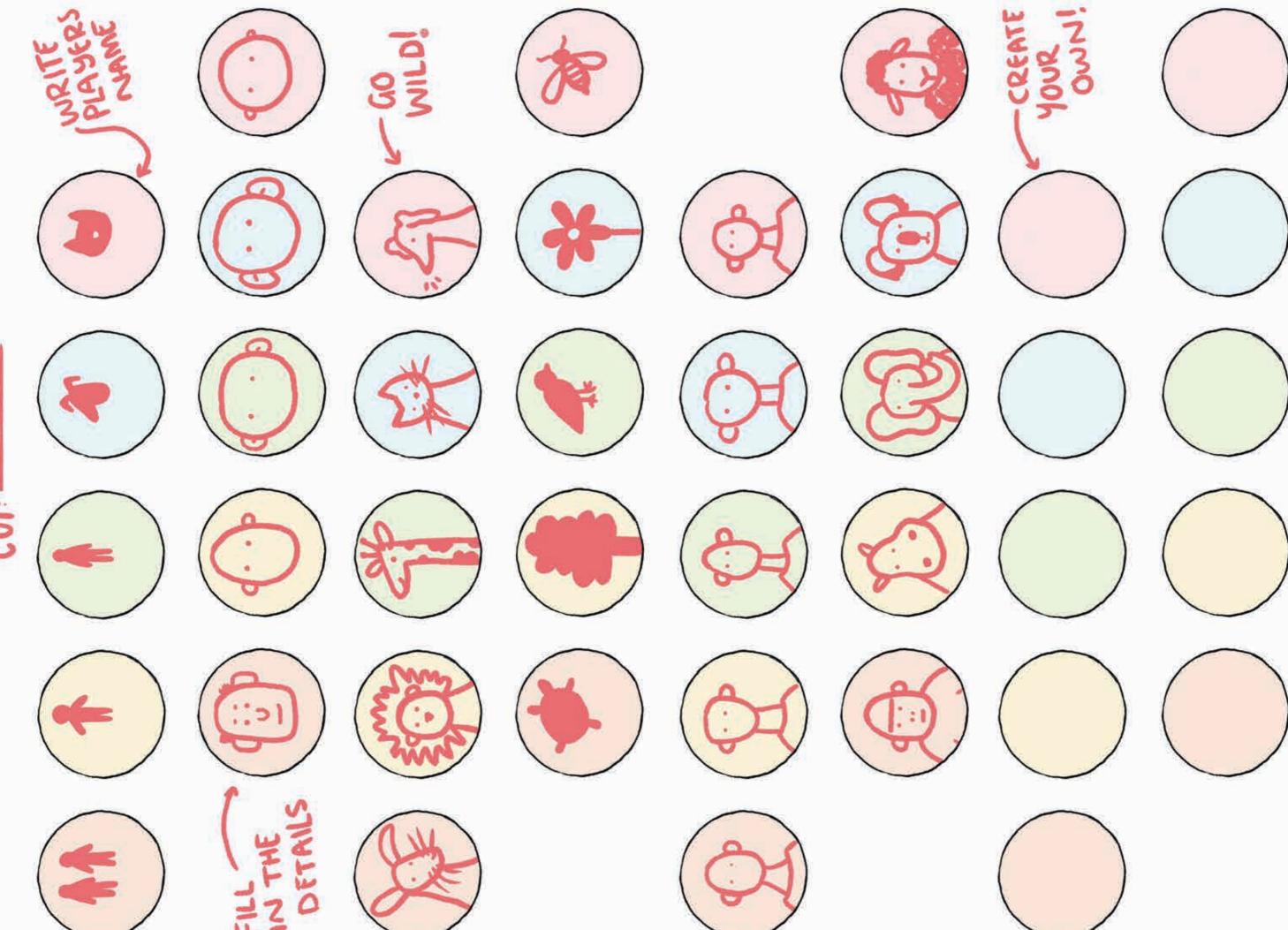
Cut out 'Allies and Friends' paper dolls. Fold them so that they can stand. They can represent people, animals, places, services and groups (go wild!) that are important in each of the life domain areas - e.g. educators and therapists that you trust, friends, or other family members, pet, or places like parks and playground. Place them inside the circle layers, with the first layer being the most important and the outermost layer being least important.

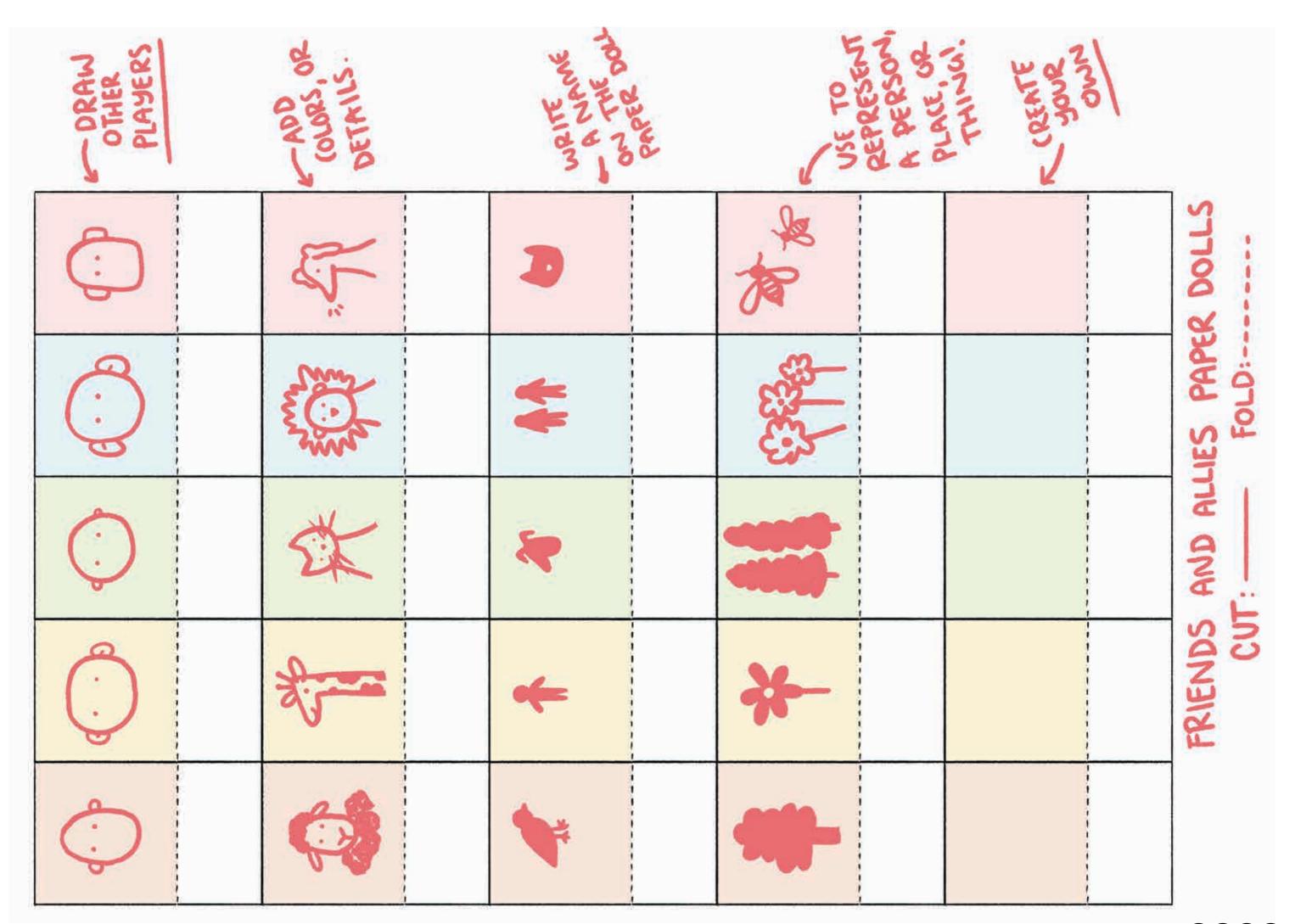


Doing this activity can help draw a more nuanced picture of your care network. We recommend doing this at a regular interval to notice any changes and record each time by taking a photograph.







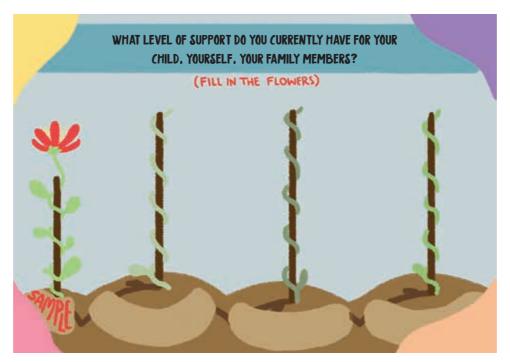


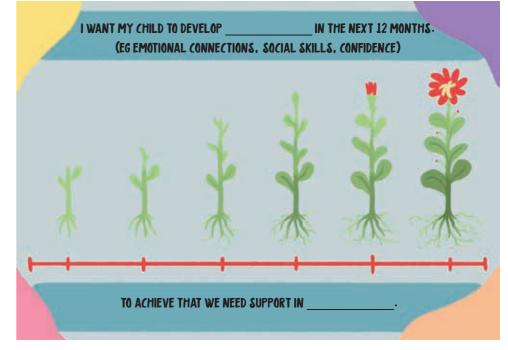


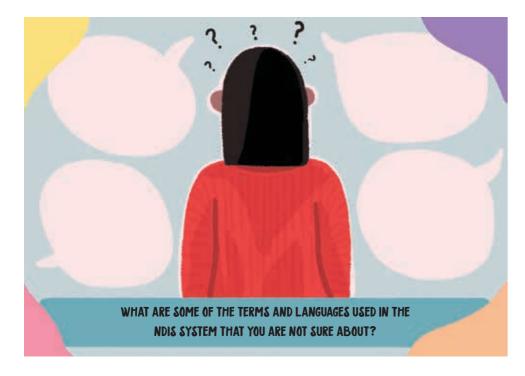




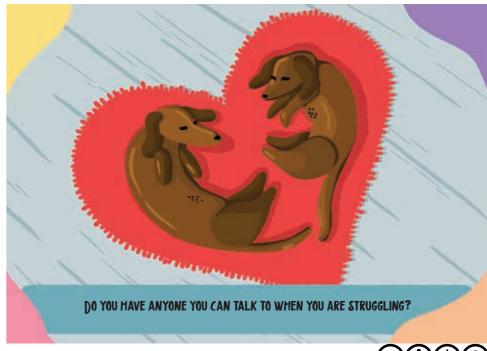






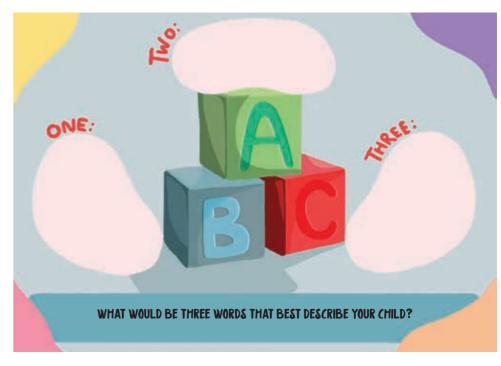






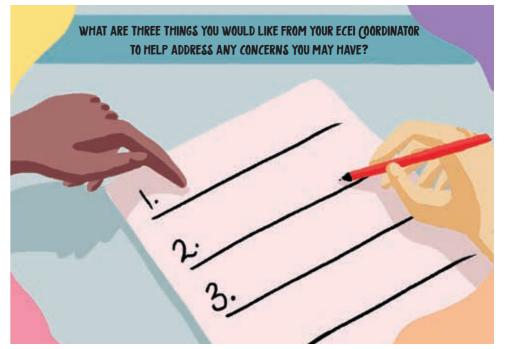














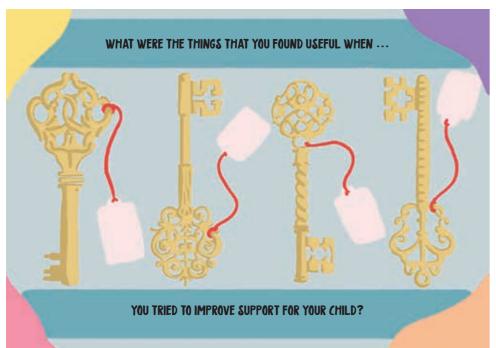














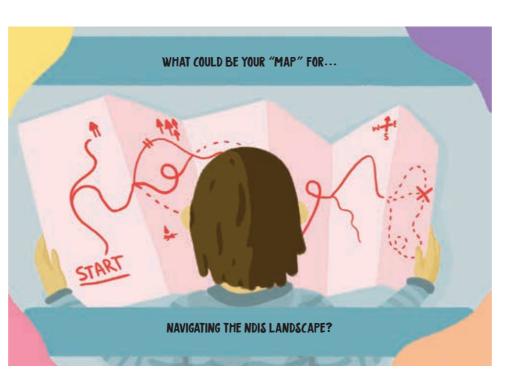




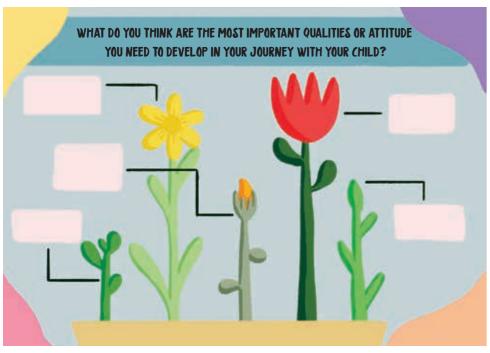


















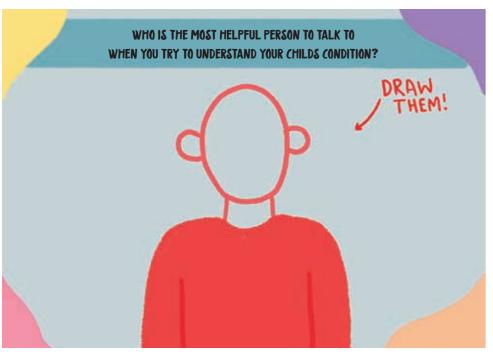












# CIRCLE OF CARE CARD





OUR LIFE IS VERY DIFFERENT FROM THE WAY WE ANTICIPATED IT TO BE.
PRIOR TO AND AROUND THE TIME OF DIAGNOSIS WE HAD
GRAND PLANS TO MOVE UP TO THE MID NORTH COAST OF NSW
AND EMBRACE A YEAR ROUND WARMER CLIMATE AND LIVE THE BEACH CULTURE.
THERE WERE OTHER THOUGHTS OF MAYBE GETTING A MOTORHOME AND TRAVELLING
AROUND AUSTRALIA FOR 12 MONTHS.

THESE PLANS AREN'T NECESSARILY IMPOSSIBLE, BUT MADE INCREDIBLY MORE DIFFICULT WITH
THE DIAGNOSIS AND OUR REALITY.

THESE PLANS WILL BE NOT CANCELLED, BUT PUT ON HOLD AT LEAST UNTIL THE

MEDIUM TERM.



# MEL'S STORY

THERE IS A LOT OF NEGATIVE IMPACT EMOTIONALLY THINKING ABOUT WHAT COULD BE WRONG WITH HIM, AND GETTING THE BAD NEWS TIME AND TIME AGAIN FROM PROFESSIONALS. WHEN WE HAD A DIAGNOSIS FOR MY SON, I DIDN'T KNOW AT FIRST WHAT THOSE WORDS MEANT, AND IT WASN'T EXPLAINED TO ME... MY HUSBAND ONCE ASKED THE PHYSIO WHO WORKS WITH MY SON: "WHAT STRENGTHS DOES A PERSON WITH CTHE CONDITION THE CHILD WAS DIAGNOSED WITH]?" THE PHYSIC SAID: "THEY ARE USUALLY FOUND TO BE CONTENT AND HAPPY CHILDREN".

MY SON CAN BE FOCUSED AND RESOURCEFUL. HE IS A HAPPY CHILD.





# REGINALD'S STORY

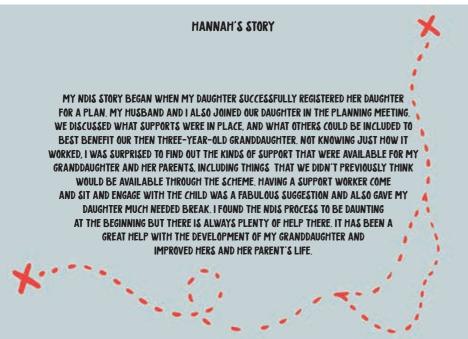
WE HAD ABSOLUTELY NO IDEA WHAT TO EXPECT FROM OUR FIRST NDIS MEETING.
WE WISHED WE'D PREPARED EMOTIONALLY FOR THE MEETING. IT WAS VARIOUSLY UPSETTING, EMBARRASSING AND
EMOTIONALLY DISTRESSING, CSOME QUESTIONS SOUNDED BLACK AND WHITE] LIKE. "CAN PATRICK USE A SPOON?"

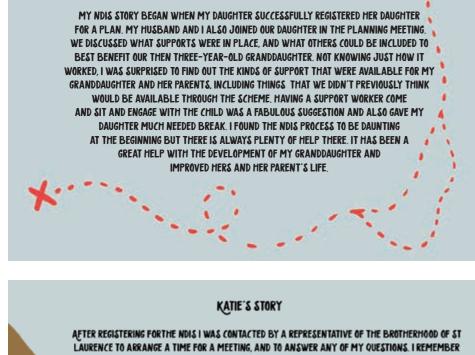
IN OUR HEADS WE THOUGHT, YES, OUR CHILD CAN USE A SPOON. HE CAN USE A SPOON TO PRETEND TO PLAY DRUMS. IF HE USES THE SPOON TO PICK UP YOGHURT OR ANYTHING ELSE A SPOON IS SPECIFICALLY DESIGNED FOR, HE SPILLS THE FOOD ALL OVER HIMSELF AND THE FLOOR. SO THE ANSWER IS NO.

### "NO. PATRICK CANNOT USE A SPOON."

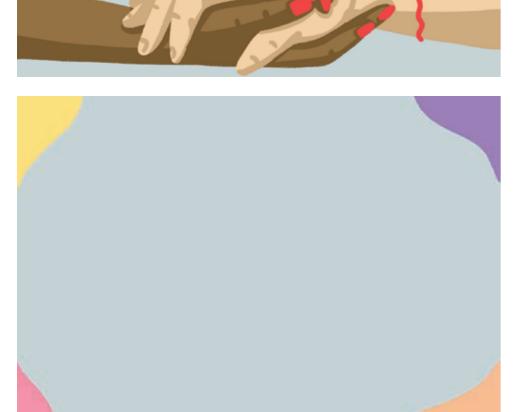
OUR ECEI COORDINATOR GUIDED US THROUGH THE NDIS PLANNING MEETING AND GAVE US AN IDEA OF WHAT TO EXPECT. ALSO, BEFORE THE MEETING, WE PREPARED A "PARENT IMPACT STATEMENT", WHICH WAS A POWERFUL WAY TO EXPLAIN HOW OUR LIVES AS PARENTS HAD BEEN IMPACTED SINCE AND LEADING UP TO THE DIAGNOSIS. IT WAS MATTER OF FACT AND IN ESSENCE GAVE US A VOICE TO HOPEFULLY HAVE THE NDIS UNDERSTAND OUR INDIVIDUAL AND IMPOUSE CIRCUMSTANCES.







# TELLING HER I WAS COMPLETELY UNPREPARED FOR WHAT WAS TO HAPPEN AT THE MEETING, AND WHAT TO ASK FOR. THE REPRESENTATIVE PUT MY MIND AT EASE AND HELD MY HAND THROUGH THE ENTIRE PROCESS, EVEN GIVING ME TIPS AND IDEAS OF WHO AND WHAT TO BRING TO THE PLANNING MEETING. SOME THINGS MY DAUGHTER WAS APPROVED FOR THAT WERE RECCOMENDED BY HER THERAPIST WERE SWIMMING AND DANCE LESSONS WHICH WILL ASSIST TO



# RACHEL'S STORY

MY SON USED TO GET FRUSTRATED AND HIT HIS HEAD, AFTER MELTDOWNS OR WHEN HE COULDN'T GET WORDS OUT, I THINK THESE WERE SOME OF THE SADDEST MOMENTS BECAUSE I DIDN'T KNOW HOW TO HELP. AND EVERYONE KEPT SAYING HE WAS FINE, BECAUSE HE DIDN'T ALWAYS DO THESE THINGS IN FRONT OF PEOPLE. OR PEOPLE SAID MY SON WAS NAUGHTY OR ANGRY, OR IT'S MY BAD PARENTING. THEN AN EARLY CHILDHOOD EDUCATOR SAIDJ "THERE IS NO NAUGHTY CHILD, THERE IS ALWAYS A REASON FOR THAT CHILD'S BEHAVIOUR, YOU JUST HAVE TO WORK WITH THE CHILD. WORK BACKWARDS TO SEE WHAT

SO, I STARTED TO KEEP A DIARY WITH DATES AND TIMES, AND WROTE EVERYTHING DOWN. I TOOK PHOTOS AND VIDEOS OF THINGS THAT HAPPENED, BUT I ALWAYS TRIED TO DO THIS WITHOUT HIM SEEING. WE COULD THEN LOOK AT WHAT HELP WAS NEEDED TO OVERCOME THE BEHAVIOUR HAPPENING AGAIN OR TO HELP TRY TO PREVENT IT. I WOULD JUST LIKE PEOPLE TO TAKE FROM MY STORY, GO WITH YOUR GUT, COLLECT YOUR EVIDENCE, STANDUP FOR WHAT YOU THINK YOU MAYBE NEED, DON'T BE SCARED. BE PREPARED, ASK QUESTIONS.



# JACKIE'S STORY

MY GRANDSON WAS PLAYING ON HIS OWN AND ALL THE EVERYDAY THINGS THAT THE OTHER GRANDCHILDREN DID AND ENJOYED JUST DIDN'T WORK FOR HIM, HIS MUM WAS GOING TO OCCUPATIONAL THERAPY, SPEECH THERAPY, GROUP ACTIVITIES - JUST SO MANY APPOINTMENTS - BUT I DIDN'T KNOW WHAT THEY WERE FOR. I TRIED TO EXPLAIN TO HIS POPPA HIS GRANDSON WAS OK, WE DIDN'T KNOW HOW TO HELP.

AN OCCUPATIONAL THERAPIST CAME TO THE HOUSE TO SEE MY GRANDSON AT HOME, TALKED TO MY DAUGHTER AND WORKED OUT WHERE HELP WAS NEEDED MOVING FORWARD. MY DAUGHTER EXPLAINED AND EDUCATED US ON WHAT WAS NEEDED AND HOW SOME SMALL CHANGES IN THE FAMILY HOME WOULD HELP. EVERYONE IN THE FAMILY NEEDS TO UNDERSTAND THE BEHAVIOURS, AND WHAT EFFECTS OUR REACTIONS TO HIS BEHAVIOURS HAVE ON HIM. TALK MORE WITHIN THE FAMILY MEMBERS NO MATTER HOW DIFFICULT IT IS, AS THIS WILL HELP EVERYONE TO NOTICE BEHAVIOURS AND HOW TO DEAL WITH THEM.









